A thesis submitted to the University of Birmingham in partial fulfilment of the regulation for the degree of

DOCTOR OF CLINICAL PSYCHOLOGY (ClinPsyD)

VOLUME I

Research Component

Understanding and Influencing Dietary Self-Care in Chronic Illness

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March 2012

Overview

This thesis is comprised of two volumes, submitted to the University of Birmingham as part of the requirements for a degree of Doctor of Clinical Psychology (ClinPsyD).

Volume I presents the research component and is made up of three papers. The first paper is a review of clinical controlled trials evaluating interventions applying psychological theory to improving dietary self-management for type 2 diabetes. The review considered whether such interventions are truly theory-based and how effective they are in changing dietary behaviour. Social Cognitive Theory was found to be the most frequently cited model by interventionists. The extent to which studies operationalised a theoretical framework varied, and there was general room for improvement here, but most demonstrated an effect for dietary behaviour change.

The second paper is an empirical study which focuses on the psychological influences on, and impact of, Coeliac Disease (CD). Participating adults completed questionnaires about their understanding (illness representation) of CD, their current health related quality of life, wellbeing and psychological health. They also rated their self-efficacy for following a gluten free diet (GFD), and the extent to which they were following their GFD (dietary self-care). Blood results for CD antibodies and dietician ratings for dietary self-care were taken at the time of participation. Results showed that some aspects of illness representation, particularly estimates of consequence and emotional impact were related to some psychosocial outcomes but not levels of dietary self-care (which was generally high among the sample). Findings related to coping and self-efficacy are also discussed.

These two papers were written with the aim of publication in the British Journal of Health Psychology (see Appendix A).

The third paper is a Public Domain Briefing Paper, this summarises the empirical study in language accessible to the general public, with the view that findings can be made available to people living with CD; and the charity Coeliac UK.

Volume II comprises the clinical component and presents four Clinical Practice Reports (CPRs). Each report reflects on an aspect of my clinical experience gained during five clinical placements across my training. Consent to anonymously present aspects of work with these clients was sort and given.

CPR1 describes the assessment and formulation stages of my work with a man aged 40 years who experienced symptoms of dread before, and panic during, social performance related situations at work. This was having a considerable impact on his sense of wellbeing and was putting his working life at risk. My client's difficulties are presented within two models; a cognitive formulation employing Clark and Wells model of social phobia (1995), then a psychodynamic formulation utilising Malan's triangles of conflict and person (1979).

CPR 2 presents a single case experimental study with a 22 year old woman who was experiencing mild to moderate obsessive compulsive symptoms. My client's difficulties were formulated within the metacognitive model of obsessive compulsive disorder (OCD). Modest reductions were found in anxiety and frustration while no statistical difference in compulsive hand washing behaviour was found between the baseline and intervention phases. Serious problems with the design are discussed together with suggestions of how the design could be improved.

CPR 3 presents a case study of my work with a 14-year-old boy referred to Child and Family Services by his Head Teacher after refusing to attend school for the first two months after the end of the summer holidays. My client's difficulties were formulated within a Beckian Cognitive Behavioural Model (Beck, 1967), with reference to specific systemic and dynamic factors that could impact on the effectiveness of an intervention. The intervention and therapy outcomes are evaluated and reflected upon.

CPR 4 presents a service evaluation comparing the usefulness of two observational tools designed to assess pain among children with moderate to severe cognitive impairments. Firstly the national planning context is examined to identify standards relevant to assessing acute discomfort among this service user group. Secondly the team generated local standards from which to evaluate the tools. Finally clinicians' impressions of the two measures are summarised.

A fifth CPR was examined through oral presentation and described my work with a 30 year old Indian woman experiencing chronic low back pain which impacted on her mood and was accompanied by worrying thoughts about her ability to cope if her pain flared up again. The abstract for this presentation is also included.

Acknowledgements

Firstly, I would like to thank all of the people who gave their time to take part in this research.

I am grateful to Ruth Howard and Jan Oyebode, my supervisors, for their enthusiastic support, expertise, and patience while I completed the research. I would also like to thank Jane Petty for helping me to organise my study materials and being an approachable fountain of knowledge.

I would like to express my gratitude to Fiona Moor, Dr Tariq Iqbal and Susan Price for taking the time and energy to support me in recruiting individuals for this research and for all the wise advice I received along the way.

Thanks to Thea for sitting with me, and to all my friends who answered the call to proof read. Particular thanks to Tracey for her formatting wizardry.

Finally I would like to thank Bob, John, Rachel, and my Mum for their endless support and for understanding my need to find the very edge of my ability. I'm done now - promise.

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How Theory-Driven and Effective are Current Self-Management Interventions for Dietary Self-care in Type 2 Diabetes?

Abstract

Purpose

To evaluate the efficacy of interventions targeting dietary self-care for type 2 diabetes mellitus (T2DM). Two key questions were asked of the reviewed studies; (a) to what extent is the intervention described theory-based, and (b) how effective are interventions based on psychological models?

Methods

Three key databases were searched for recent papers describing randomised controlled trials that applied a named psychological theory or construct to improving dietary self-care for T2DM. Seventeen papers meeting the inclusion criteria were subjected to examination of quality, theory application (with reference to the Theory Coding System; Michie & Prestwich, 2010), and effectiveness.

Results

The most commonly named theory was the Social-Cognitive Theory. The most popular construct was self-efficacy. Papers varied in term of the extent to which, (a) theoretical hypothesis were set, (b) predictor variables were measured (d) theory explicitly informed intervention, and (c) results were interpreted in the light of theory. Few papers paid attention to theory evaluation. Nevertheless, most studies reported small to moderate short-term treatment effects relevant to dietary self-care, in addition to improvements in other outcomes.

Conclusions

Interventions based on psychological theory are modestly effective in improving dietary self-care for T2DM. Current hypotheses tend to refer to whether an intervention, based on a named theory or construct, is effect or not. To improve future theory, practice and results, there may be benefit in operationalising theory more explicitly within future study designs.

Introduction

Diabetes mellitus is a common chronic condition characterised by abnormally high levels of glucose (or sugar) in the blood (Sperry, 2009). Recent figures from 2010 estimate the prevalence of diabetes in the UK at 4.26% of the population (Diabetes UK, 2011). Causation is both genetic and environmental (Gonder-Frederick, Cox, & Rimmerband, 2002; Neel & Sargis, 2011) and many authors attribute the growing prevalence of the condition to increases in obesity, reduced physical activity levels, and longer life expectancy among the general population (Sperry, 2009; Wild, Roglic, Green, Sicree, & King, 2004). This review introduces diabetes and the importance of self-management in the context of previous research and review, before narrowing the focus to the specific aims, rationale and methodology for the current review. The results section then describes the reviewed papers with reference to these aims and explicit evaluation is provided in the discussion.

In diabetes abnormally high blood glucose (hyperglycaemia) occurs when insufficient or ineffective insulin is secreted by the pancreas to balance sugar levels in the blood (Sperry, 2009). Type 1 diabetes mellitus (T1DM) is usually diagnosed at a young age and results from an impaired ability of the pancreas to produce insulin. The resulting hyperglycaemia is treated with daily self-administered injections of insulin and regular blood glucose monitoring. Diabetes mellitus type 2 (T2DM) is much more common than T1DM and usually onsets in adulthood after the age of 40 years (Hampson, 1997). Insulin deficiency can also occur in T2DM but the condition more often results from insulin resistance. This means that the cells of the body are unable to make use of the insulin that is available. The treatment for T2DM is first diet and exercise, then medication (if any).

Failure to maintain a normal blood sugar can have numerous serious consequences. Complications include coronary heart disease (CHD; UK Prospective Diabetes Study Group, 2009), kidney failure (Hummer, Vannatta, & Thompson, 2011), and peripheral neuropathy which is the main cause of lower limb amputation (Molitch et al., 2004; Sakraida & Robinson, 2009). Diabetes is also a major cause of blindness (Sperry, 2009). Psychosocial consequences such as anxiety and depression have also been found (Williams, Clouse & Lustman, 2006). The treatment of T2DM and its complications represents a considerable financial burden (Norris et al., 2002). For these reasons, self -management is critical in diabetes care (Ellis et al., 2004).

In common with other chronic health conditions, self-management of diabetes requires a high level of health literacy and autonomy. Diabetes also requires the individual to make multiple complex decisions about behaviour, and to generate, set, work through, and evaluate daily behavioural goals (Lorig & Holman, 2003). Diet is a vital component of self-management in T2DM (Clark, Hampson, Avery, & Simpson, 2004) as it is often managed by diet and exercise alone (Petrie, Broadbent & Meechan, 2003). While there is a significant hereditary component to T2DM, the condition can often be precipitated by unhealthy eating and weight gain (Povey & Clark-Carter, 2007). Thus changing to a healthy eating plan may require considerable effort and motivation. Indeed evidence suggests that across chronic health conditions requiring specific diet behaviour, people find it very difficult to change their eating habits (Burke, Dunbar-Jacob, Orchard, & Sereika, 2005; Luszczynska, Scholz, & Sutton, 2007). These difficulties are further exacerbated in people with diabetes, as individuals get little immediate feedback from good self-management behaviours (Sperry, 2009). Unfortunately, while following a good self-management plan improves glycaemic

control, it does not automatically lead to good glycaemic control (Petrie et al., 2003). Understandably this situation can lead to frustration, anxiety, and fluctuating motivation and self-efficacy to self-manage the condition (Sperry, 2009).

Since the early 1990s diabetes (both T1DM and T2DM) has been the focus of a large number of intervention studies (Glasgow, Toobert, Hampson, & Noell, 1995; Bastiaens et al., 2009; Glasgow & Toobert, 2000; Schwedes, Siebolds, & Mertes, 2002) and self-management of diabetes warrants and attracts frequent review (Clark, 2008). These reviews tend to focus on the efficacy of interventions in improving glycaemic control (Steed, Cooke, & Newman, 2003). Over time, there has been a shift in intervention approach from didactic educational delivery to more theory driven, empowerment based, collaborative interventions (Norris, Engelgau, & Narayan, 2001). This is reflected in the National Standards for Diabetes Self-management Education guiding principles (Clark, 2008).

A number of key reviews have concluded that self-management interventions can be modestly effective at least in the short term (Gary, Genkinger, Peyrot, & Brancati, 2003; Ellis et al., 2004; Norris et al., 2001; Steed et al., 2003). However, differences in the intervention components, delivery mode, outcome measures, intervention periods and follow-up times across studies make it difficult to make generalisations and limit the conclusions that can be drawn (Gary et al., 2003). Another factor which limits findings is combining diabetes types 1 and 2 in research. Povey and Clark-Carter (2007) reviewed 20 interventions specifically targeting diet in diabetes. They commented that despite T1DM and T2DM having different biological mechanisms and dietary requirements, almost all studies had pooled samples. Targets for intervention also varied considerably across studies and the lack of detailed

information about the interventions made it difficult to synthesise the findings across studies. To increase the efficacy of diabetes care, there will be a need to look closely at the efficacy of individual components within interventions (Steed et al, 2001).

Steed et al. (2003) reviewed the psychosocial outcomes of 36 self-management interventions for T2DM. They concluded that psychological interventions tend to target psychosocial outcomes such as wellbeing or quality of life, or process variables that mediate behavioural change, such as self-efficacy or locus of control. These psychosocial interventions also tend to target diabetes samples with psychological distress such as depression and anxiety. In contrast, educational interventions tend to target behaviour change and the biological markers of glycaemic control (e.g., HbA1c) in patients with poor self-management or poorly controlled blood sugar levels. Heinrich and Schaper (2010) reviewed 14 self-management interventions for T2DM. Only 7 of the reviewed studies gave a theoretical background to their intervention, while another 4 studies made mention of psychological concepts such as self-efficacy without embedding these within a theory.

Heinrich & Schaper (2010) concluded that the area has turned increasingly to psychological theory to direct self-management interventions, yet the extent to which self-management interventions are driven by psychological theory varies greatly. Current self-management intervention is not devoid of psychology, nevertheless psychological principles are often not explicitly operationalised within intervention studies; improved self-management may benefit from doing this in future research (Michie & Prestwich, 2010).

Recently Michie and Prestwich (2010) spelt out the importance of applying theory to intervention as a means of directing intervention research toward theoretically meaningful

targets thus providing a framework for interpreting findings, and developing theory in the light of findings. These authors developed the Theory Coding System (TCS) to support interventionists and reviewers assess the "extent to which behavioural interventions are theory-based" (Michie & Prestwich, 2010, p. 1). This coding scheme comprises of 19 codes for identifying the extent to which researchers 1) base their intervention on a named theory, model, or component thereof, 2) describe how this theory informed intervention techniques, 3) measure proposed predictor variables pre and post intervention with validated tools, 4) discuss findings in the light of theory, and 5) evaluate the clinical validity of theory on the basis of results. A description of theories most commonly applied to behaviour change, and their component constructs, was made available on request by Michie and Prestwich (2010) and this available in Appendix B, together with a table based on the TCS codes.

Aims

Previous reviewers have commented that pooled samples and the multi-component nature of diabetes interventions have limited possible conclusions. Self-management of diabetes is complex and warrants a multicomponent approach to intervention. While this review will comment on non-dietary targets of intervention, most attention will be given to dietary self-care. Building on the recent review by Heinrich & Schaper (2010) this paper will employ Michie and Prestwich's (2010) Theory Coding System to guide a review of intervention studies that apply psychological theory to improving dietary self-management among adults with T2DM. As interventions have changed over time and an overwhelming number of reviews have covered the period up to 2006, this review will be restricted to

recent intervention studies. Restricting the review to randomised control trials (RCTs) keeps quality homogeneous and allows for more valid comparison of the interventions used (Norris et al., 2001). Conclusions will focus on 1) the extent to which the intervention described is driven by psychological theory, and 2) the extent to which the findings reported demonstrate a treatment effect. The design and quality of the papers will also be commented on. Finally, this should allow for general conclusions about the effectiveness of applying psychological theory in supporting dietary self-care among people with T2DM.

Method

Three data bases (Psycinfo, Embase, and CINAHL) were searched to identify published articles evaluating self-management interventions for diabetes. The search terms used (presented in Table 1) were based on those used by Povey and Clark-Carter (2007) in their review of healthy eating interventions for diabetes. Reference lists of reviews and retrieved papers were hand-searched.

Table 1: Key Words Employed to Identify Studies by Population, Intervention, Comparison and Outcome.

Population	Diabetes mellitus/diabetes/type 2
Intervention	Self-management/self-care/self-regulation/
Comparison	Randomised Control Trial/clinical trial/intervention/intervention study
Outcome	Diet/dietary/eating behaviour/food intake/

As in Norris et al. (2001) titles of initial retrievals (447) were reviewed for their relevance to self-management interventions for adults with T2DM. This resulted in 84 abstracts, from which 26 full papers were obtained and from these 17 were found to meet the inclusion criteria, presented in Table 2.

Table 2: Inclusion and Exclusion Criteria for Literature Review.

Year and language	Peer-reviewed studies published in English between January 2006 and December 2011
Sample	Adults with medically diagnosed type 2 diabetes mellitus
Intervention	The paper must describe the intervention as being based on at least one psychological theory or concept. Any medium or delivery mode (individual, group, telephone, internet, written material, correspondence)
Study design	Must report findings of a randomised controlled trial (RCT).
Outcomes	Must report outcomes relevant to an assessment of dietary self-care (e.g., marker of glycaemic control, saturated fat intake, total fat intake, blood lipids, body mass index (BMI), body weight, food diary, self-reported dietary behaviour)
Exclusion criteria	Case studies, non-controlled studies, studies comparing two interventions with no control group, studies described in editorials, commentaries or dissertation abstracts, studies with samples including DMT1 or other chronic conditions. Drug trials.

Results

In order to address the review questions this section will summarise information across the reviewed papers relating to population, quality of design, theoretical background, and main dietary and non-dietary outcomes. A description of each study is presented in Table 3. The self-report measures across the studies are listed in Table 4, and intervention targets, by study, are detailed in Table 5.

Sample Characteristics

Across the studies more women (1633) than men (1016) participated, although, in 6 of the studies gender was evenly matched. Toobert et al. (2007) recruited only women. The mean age reported ranged from 45 years to 65 years. Studies were conducted in America (10 studies), the Netherlands (2 studies), Japan (1 study), China (1 study), Taiwan (1 study) and the UK (2 studies). Participants across the studies were predominantly white. Other

reported ethnic origins were African American (Davis et al, 2010; Hawkins, 2010), Chinese (Shi, Otswald & Wang, 2009) Taiwanese (Wu et al., 2011), Hispanic (Osborn et al., 2011), Latin American (Rosa et al., 2011), and Japanese (Moriyama et al., 2009). All studies recruited people who had been medically diagnosed with T2DM for at least 3 months. Most studies used inclusion criteria to select samples with a high CHD risk profile. Hawkins (2010) explicitly recruited older adults reasoning that this group "experience the greatest burden of diabetes" p. 217. Across the studies, the mean baseline levels of glycosylated haemoglobin (HbA1c or A1c) ranged from 6.5% - 9% (below 7% is recommended), and the mean body mass index for most studies ranged from 32-38 (optimal would be 21-25). In contrast, Shi et al. (2010) employed a sample with a mean BMI of 25.

Table 3: Summary of Psychological Approaches and Methodologies Employed in the Reviewed Studies

Reference (Country)	Theoretical Background	Design	Sample Size	Intervention	Outcome Measures	Findings
Dale Caramlau, Sturt, Friede, & Walker, 2009 (UK)	Self-efficacy Motivational interviewing	RCT w 3 conditions	231 Usual care (n=97, attrition 6) Peer-support (n=90, attrition 6) Nurse support (n=44, attrition 6)	Telephone support (at least 6 calls over 150 days)	Self-efficacy Glycaemic control (HbA1c) Diabetes distress (PAID)	No groups differences
Davis et al., 2010 (South Carolina, USA)	Health Beliefs Model Transtheoretical Model	RCT w 2 conditions	165 (attrition 0) Usual care (n=80) Intervention (n=85)	13 session intervention (3 Individual and 10 group); 3 sessions conducted in person; 10 session via video conferencing (12 month duration)	Glycaemic control (GHb); LDL Cholesterol; Blood Pressure; BMI; Waist Circumference; Albumin-to-creatinin ratio	Sig improvement in glycaemic control at 6 months and 12 months for intervention but not control group. Sig improvements in cholesterol levels for intervention group but not the control group at 12 months. No other group differences
Faridi et al., 2008 (Connecticut, USA)	Self-efficacy	RCT w 2 conditions	30 (attrition 0) Usual care (n = 15) Intervention (n=15)	Novel Cell-phone technology for Health Enhancement (NICHE); Pts trained to upload daily blood tests and pedometer readings. Tailored Feedback received	Glycaemic Control; Blood pressure; BMI; Weight; Exercise Diabetes self-efficacy	Sig increase in diabetes self-efficacy for intervention but not control group
Glasgow et al., 2006 (Denver, USA)	Social-Cognitive Theory Self-efficacy	RTC w 2 conditions	335 Usual care (n = 143, attrition 13) Intervention (n =153, (attrition 21)	Single Interactive CD-ROM session. Information then guide coaching session; follow-up calls as required Tailored newsletter at 6 weeks.	Self-reported fat intake; Self-reported fruit/Veg intake; Glycaemic control (HbA1c); Depression (PHQ)	Self-reported fat intake and measured weight reduced in both groups but significantly more in intervention group than control. Clinically relevant reductions in HbA1c, lipids and Depression favouring intervention did not reach significance. No other differences found

Reference (Country)	Theoretical Background	Design	Sample Size	Intervention	Outcome Measures	Findings
Hawkins, 2010 (USA)	Social-Cognitive Theory Transtheoretical Model Motivational interviewing Self-efficacy	RCT w 2 conditions	76 Attentional Control (n= 36, attrition 4) Intervention (n=40, attrition 6)	Weekly 15-minute videophone sessions with nurse trained in MI for 3 months. Then monthly videophone sessions for further 3 months	HbAlc; Cholesterol; BMI; Blood pressure; Self-efficacy; Diabetes Knowledge	Sizable treatment effect found for glycaemic control but no other clinical outcomes. Self-efficacy significantly increased for intervention group only. Diabetes knowledge increased in both groups but this was only significant in the treatment group. Time, group, self-efficacy analyses showed interaction such that in Tx higher SE associated with greater improvement in GC
Huisman et al., 2009 (Netherlands)	Self Regulation Motivational interviewing	RCT w 3 conditions Outcomes assessed at 3 and 6 months	129 Usual care (n=38) Usual care plus self help guide (n=38) Intervention (n=53) Attrition 67% by 6mths	1 x Motivational Interview (1 hr). 6 x Group sessions (2 hr). Two booster group sessions within 1 year. Use of pedometer	Glycaemic control; BMI Self regulation skills; Exercise Diabetes Quality of life; Nutrition	Tx effect for exercise only. Across groups low self regulators showed lower glycaemic control at 3 and 6 months.
Keogh et al., 2011 (Ireland)	Self Regulatory Model Motivational Interviewing	RCT w 2 conditions	121 Usual care (n= 49, attrition 11) Intervention (n= 53, attrition 8)	2 x 45 minute family sessions (with one family member or chosen friend) at home with Health Psychologist plus 1 follow up call (15 minutes).	Self reported Glycaemic control; Self reported diet; Psychological wellbeing; Family support; Diabetes beliefs; BMI	Tx for Glycaemic control (modest effect); Self reported Diet; BMI; Psychological wellbeing; Family support; Diabetes beliefs (increased personal and treatment control beliefs, lower diabetes distress and increased understanding,). No change in beliefs about consequence or timeline)
Lorig, Ritter, Villa, & Armas, 2009 (USA)	Self-efficacy "Theory"	RCT w 2 conditions 12 months follow up, intervention group only	352 Usual care (n= 133, attrition 26) Intervention (n= 161, attrition 25)	6 weekly peer-led community group sessions (2 ½ hrs) Manualised protocol	Glycaemic control; Self-reported hyper/hypoglycaemic symptoms; Fatigue; Depression; Self-efficacy; Multiple Self-management behaviours	At 6 mths: No Tx effect for glycaemic control. Tx effect for depression. Tx effect for self-efficacy and patient activation. Tx for some self-management behaviours (healthy eating, communicating with physicians, reading food labels, glucose monitoring, exercise). At 12 month Follow Up: Tx group showed continued improvement from baseline in depression, self-efficacy, patient activation, healthy eating communication with physician (no control comparison)

Reference (Country)	Theoretical Background	Design	Sample Size	Intervention	Outcome Measures	Findings
Miller & Gutschall, 2009 (Ohio, USA)	Social-Cognitive Theory	RCT w 2 conditions	109 (attrition = 6) Waiting list (n =48) Intervention (n=55)	9 week group program (1.5/2 hr); Family members invited to all groups.	Empowerment; Self-efficacy (for diet, exercise, self- medication, self-regulation); Outcome expectancy (dietary self-care barriers, glycaemic control, family support, glucose monitoring); Dietary intake.	Significant improvements across all variables in favour of the immediate intervention group over the delayed intervention group. Improvement replicated for delayed group post intervention (no control group). Improvement retained at 9 week follow up for immediate intervention group--all variables except self-efficacy for self-regulation.
Moriyama et al 2009 Japan	Transtheoretical Model Motivational Interviewing Self-efficacy	RCT w 2 conditions	65 Usual care (n =25, attrition 2) Intervention (n = 50, attrition 8)	12 x monthly individual motivational interviews with diabetes educator.	Glycaemic control; Blood Pressure Self reported dietary self-care; Food label reading; Physical activity; Self-efficacy.	Tx for Glycaemic control. Non-sig difference in diastolic blood pressure in favour of intervention group. Tx for self reported dietary self-care. Tx for food label reading. Tx for physical activity. Tx for Self-efficacy
Osborn et al., 2011 (North East USA)	Information-Motivation-Behavioural Skills Model Motivational Interviewing	RCT w 2 conditions	91 Usual care (n = 43, attrition 16) Intervention (n = 48, attrition 11)	1 x 90-minute session with medical assistant trained in MI. Feedback paperwork	Glycaemic control; Dietary self-care (food label reading, dietary self-care, physical activity).	Tx for glycaemic control. Tx for food label reading and self reported dietary self-care. Positive trend but no significant Tx effect for physical activity.
Rosal et al 2011 Massachusetts USA	Social-Cognitive Theory Self-efficacy Diabetes Knowledge	RCT w 2 conditions	252 (attrition 0) Usual care (n = 128) Intervention (n = 124)	12 month intervention. One individual home session, 11 weekly group sessions followed by 8 monthly group sessions	Glycaemic control; Cholesterol ; BMI & waist circumference; Self monitoring; 24hr dietary recall; Physical activity; Self-efficacy; Diabetes Knowledge.	Small Tx effect compared to control for HbA1c at 4 months, this was non- significant at 12 months. HbA1c was significantly reduced from baseline in both groups at 4 and 12 months. Tx effect for self reported dietary self-care at 4 and 12 months compared to control. Tx for self monitoring of blood glucose at 4 and 12 months. Tx effects for self-efficacy and diabetes knowledge at 4 and 12 months. No Tx for cholesterol, BMI or waist circumference.

Reference (Country)	Theoretical Background	Design	Sample Size	Intervention	Outcome Measures	Findings
Sacco et al., 2009 (Florida, USA)	Social-Cognitive Theory Social Learning Theory Self-regulation Goal; Implementation Reinforcement (Operant conditioning) Awareness of goal discrepancies (Control theory)	RCT w 2 conditions	62 Usual care (n = 27, (attrition 4) Intervention (n = 21, attrition 10)	Weekly telephone coaching for 3 months by paraprofessionals (trained and supervised by Psychologist) Fortnightly telephone coaching for further 3 months	Glycaemic control; BMI; Depression; Diet; Exercise; Foot care; Self-efficacy; Diabetes Knowledge; Awareness of goal discrepancies; Perceives social support; Reinforcement for goal behaviour.	Moderate treatment effect found for foot care. Modest effect found for other behavioural outcomes. No significant changes in glycaemic control or BMI. Modest treatment effect found for all psychosocial outcomes. Self-efficacy mediated reduction in depression scores.
Shi, Otswald & Wang, 2009 (China)	Self-efficacy "theory" Health Beliefs	RCT w 2 conditions 4 month follow up	157 (attrition 0) Usual care (n = 80) Intervention (n = 77)	1 month hospital clinic based 4 x 1-2 hour group sessions	Self-efficacy; Self reported Glycaemic control behaviour	Tx for self-efficacy at 4 months post intervention. Treatment effect found for self reported glycaemic control behaviour at 4 months post intervention.
Thoolen, Rider, Bensing, Gorter, & Rutter, 2009 (Netherlands)	Social-Cognitive Theory Self Regulation	RCT w 2 conditions	197 Usual care (n=102, attrition 12) Intervention (n=78, attrition 11)	2 individual and 4 group (2 hours) sessions delivered by nurse	Intentions; Self-efficacy; Proactive coping; self-care (for diet/exercise/medication); Body weight.	Significant (medium to large) effects found for all outcome variable at 3 months and 12 months
Toobert et al., 2007 (Oregon, USA)	Social-Cognitive Theory	RCT w 2 conditions	279 (attrition 42) Usual care (n = 116) Intervention (n = 163)	Weekly 4-hour groups session for 6 months with lay group facilitator, dietician and exercise coach. Then either, (a) Reducing schedule of lay support group meetings, or (b) 4 meetings with interventionists over 18 months to create tailored computer-assisted program	Self-reported Dietary intake; Self-reported Physical activity; Self-reported Stress management practices; Social and environmental sources of support.	Improvements across all behavioural measures in favour of Tx group over control, maintained at 12 and 24 months follow up. Smaller improvements across psychosocial measures found for Tx, maintained at 12 & 24 months. No significant differences found between maintenance conditions

Reference (Country)	Theoretical Background	Design	Sample Size	Intervention	Outcome Measures	Findings
Wu et al., 2011 (Taiwan)	Social-Cognitive Theory Self-efficacy	RCT w 2 conditions	158 (attrition 13) Usual care (n = 73) Usual care plus Intervention (n = 72)	4 x weekly group sessions Plus telephone follow-up sessions (10-15 mins) at 8 and 16 weeks.	Self-efficacy; Outcome expectations; Self reported self-care (diet and exercise); Number of diabetes symptom related emergency health care attendances	Tx effects for intervention over control group across all outcomes at 3 and 6 months. No significant difference in emergency health care requirements due to diabetes
Tx = Treatment Effect, GC = Glycaemic Control, SE = Self-efficacy						

Quality of the Studies

Studies were included on the basis of employing a between subjects control group. Of the seventeen studies reviewed, fifteen employed a usual care control. Miller and Gutschall (2009) used a delayed treatment group, and Hawkins (2010) employed a control group that experienced similar but much less frequent (videophone) contact than the intervention group. All studies claimed randomisation to avoid selection bias but less than half described their randomisation method. Those that did described methods including automated randomisation (Glasgow et al., 2006) random number tables (Keogh et al., 2011; Wu et al., 2011), use of opaque envelopes (Dale, Caramlau, Sturt, Friede, & Walker, 2009; Shi et al., 2010), referral order (Moriyama et al., 2009), and assignment by health centre (Faridi et al., 2008). In Rosa et al. (2011) randomisation was stratified by site, gender, HbA1c level and insurance cover. Most studies, however, reported non-significant between group comparisons across a number of demographic and outcome variables at baseline. Only one study (Moriyama et al., 2009) reported potential selection bias. As regards potential detection bias, it would have been difficult to keep participants or intervention assessors blind to allocation. Four studies did attempt to avoid detection bias by double blinding baseline assessments (Hawkins, 2010; Osborn et al., 2011; Keogh et al., 2011) and, or, having outcome assessors blind to condition (Miller & Gutschall, 2009, Keogh et al., 2011). Most of the studies had attrition rates upwards of 10% but this was usually evenly spread across conditions. To offset potential attrition bias four studies used “intention to treat” analysis to accommodate uneven attrition rates across their groups (Glasgow et al., 2006; Lorig, Ritter, Villa, & Armas, 2009; Thoolen, Rider, Bensing, Gorter, & Rutter, 2009). Most studies did not

compare the baseline characteristics of participants and non-participants (i.e., those meeting the inclusion criteria within the population targeted but not recruited into the study). The two studies that did this found no significant differences (Dale et al., 2009; Glasgow et al., 2006). Finally, samples sizes varied widely with only four studies reaching the sample size required for their desired effect size (Glasgow et al., 2006; Lorig et al., 2009; Toobert et al., 2009; Wu et al., 2011). Thoolen et al. (2009) was the only study to provide effect sizes for each of their findings. Sample size across the studies ranged from 30 to 352.

Theoretical Background of the Studies

This section reviews the papers with reference to the Theory Coding System provided by Michie and Prestwich (2010). The nineteen codes were summarised by the authors into six key questions and these will form the structure of this section. The first question, concerning whether a theory or construct is named, was an inclusion criteria for this review.

Which Theory or Theoretical Construct is Named?

Most studies cited more than one theory or construct to support interventions. These are presented in Table 3. The Social Cognitive Theory (SCT; Bandura, 1977) was the most frequently cited theoretical background, cited in eight studies (Glasgow et al., 2006; Hawkins, 2010; Miller & Gutschall, 2009; Rosa et al., 2011; Sacco et al., 2009; Thoolen et al., 2009; Toobert et al., 2007; Wu et al., 2011). Three studies based interventions on the Transtheoretical Model (TTM; Davis et al., 2010; Hawkins, 2010, Moriyama et al., 2009). Self regulation (SR) principles were applied in three studies (Huisman et al., 2009; Keogh et al., 2011; Thoolen et al., 2009) and one study used the Health Belief Model (Davis et al., 2010). Osborn et al. (2011) employed the Information-Motivation-Behavioural Skills model (e.g.,

Reid & Aiken, 2011) which they explain is a general social psychology model comprised of the key conceptual elements found to improve health behaviours across the SCT, TTM, and the Theory of Planned Behaviour. Of the other theoretical constructs introduced, self-efficacy was by far most frequently mentioned and measured (thirteen studies). In three studies self-efficacy was the only named construct (Faridi et al., 2008; Lorig et al., 2009; Shi et al., 2010). Motivational interviewing (Dale et al., 2009; Hawkins, 2010; Huisman et al.,2009; Keogh et al., 2011; Moriyama et al., 2009; Osborn et al., 2011), and empowerment (Moriyama et al. 2009) are also mentioned. Finally one study (Sacco et al 2009) introduces, in addition to SCT, a number of other concepts including self-regulation, operant conditioning, goal implementation, and goal discrepancies.

Are the Relevant Theoretical Concepts Targeted?

Theoretically relevant constructs to target when applying the SCT include self-efficacy (self-confidence in performing behaviour change), behavioural capability (knowledge and skill required for behaviour change), outcome expectancies (expectation and perceived value of outcome), and barriers (i.e., real or perceived obstacles) (Michie & Prestwich, 2010; Redding, Rossi, Rossi, Velicer, & Prochaska, 2000). All of the papers that claimed to apply the SCT targeted self-efficacy. Four studies targeted Diabetes-specific knowledge (Hawkins, 2010; Miller & Gutschall, 2009; Rosal et al., 2001; Sacco et al., 2009). Outcome expectations were targeted by two studies (Miller & Gutschall, 2009; Wu et al., 2011). Sacco et al. (2009) also targeted non SCT constructs including social support, social reinforcement (operant learning theory), and awareness of discrepancy between valued goals and actual performance. In contrast, four studies did not explicitly target any SCT construct but did

measure self-efficacy as an outcome variable (Dale et al., 2009; Faridi et al., 2008; Lorig et al., 2009; Shi et al., 2010). Two studies (Glasgow et al., 2006; Toobert et al., 2007) named the SCT but referred the reader to previous publications for a description of their theoretical background while their current write-up was unclear about what psychological constructs they were targeting (if any).

Relevant theoretical concepts to assess or target when applying the TTM include the 5 stages of change (pre-contemplation, contemplation, action, maintenance, and relapse), decisional balance and self-efficacy (Redding et al., 2000). Moriyama et al. (2010) was the only study that explicitly targeted all these constructs. Despite claiming their intervention was informed by two psychological theories, the Health Belief Model and the Transtheoretical Model, Davis et al. (2010) did not target any TTM constructs or health beliefs. Similarly, Hawkins (2010) proposed that motivational interviewing is based on the SCT and TTM, but did not explain how or target any SCT or TTM constructs.

Self regulation encompasses a number of diverse approaches. Common to all is the idea of a dynamic cognitive, emotional, and behavioural process of goal pursuit with reference to motivation, and feedback (Cameron & Leventhal, 1997). Keogh et al. (2011) explicitly target relevant concepts within the Self Regulatory Model (i.e., illness representations which include illness identity, coherence, timeline, consequence, causation, personal and treatment control, and emotional representations). They did not, however, investigate the relevance of coping, which has been proposed to mediate the influence of illness representations on outcomes (Hagger & Orbell, 2003). Thoolen et al. (2009) targeted the concept of proactive coping (future planning for anticipated obstacles to goal attainment

and maintenance) which the authors attribute to the Self Regulatory perspective. Huisman et al. (2009) targeted what they call "feedforward" mechanisms (self-efficacy) and feedback mechanisms (self-monitoring). In addition to targeting SCT concepts, Moriyama et al. (2009) also targeted self-regulation behaviour. It is worth noting here that, although only three studies explicitly named self-regulation, almost all of the reviewed studies targeted goal setting behaviour.

Do Studies Describe How Theory Informed intervention Techniques?

A SCT intervention would be reasonably expected to assess, and target improvements in, self-efficacy, outcome expectations, self-evaluation, and self-management capability. Miller and Gutschall (2009) made clear links to theory when describing how their intervention used paced discussions to a) increase diabetes-relevant-knowledge, and b) facilitate discussion around self-efficacy and outcome expectations for a range of self-care behaviours. Similarly, three other studies targeted knowledge, behavioural capability and self-efficacy by; explaining, demonstrating, and providing real and vicarious experience in, how to manage diabetes (Rosal et al., 2011; Shi et al., 2010; and Wu et al., 2011). Four studies (Glasgow et al., 2006; Hawkins, 2010; Sacco et al., 2009; Toobert et al., 2007) make no explicit links between SCT and intervention but described interventions that clearly reflected some SCT concepts; for example, in Glasgow et al. (2006) a single computer assisted session guided participants through an interactive process of identifying benefits, and dealing with barriers, to a personal goal selected from and list of healthy diet and exercise options.

Of the three studies naming the TTM, Moriyama et al. (2009) make the clearest

theory practice links. Having assessed participants' stage of change an intervention model was based on the premise that (a) increased understanding of their condition, (b) self-monitoring of biological feedback, and (c) improved self-care skills would support a decisional balance towards healthy behaviour change. Despite naming the SCT and the TTM, Hawkins (2010) gives more attention to the conceptual basis for the motivational interviewing style she used. This featured positive feedback, none judgemental and accurate listening, and giving the responsibility for change back to the participant.

All the studies naming self regulation described clear theory-practice links. In Keogh et al. (2011) a Health Psychologist applied cognitive and motivational techniques to challenge unhelpful or inaccurate illness beliefs and facilitate motivation for self regulatory behaviour based on more helpful illness representations. Thoolen et al. (2009) clearly apply their proactive coping concept within their self regulation intervention. Groups focussed on valued goals and facilitated participants in developing personal 5 step proactive coping plans based on identified barriers and prerequisites to goal achievement. Huisman et al. (2009) employed a motivational interviewing and psychoeducational approach to support participants in setting personally valued goals and increasing their self-regulation skills.

Osborn et al. (2011) was the only paper to apply the IMB model and describe how a single 90 minute session targeted each of the three components; information, motivation, and behavioural skills.

In contrast to the above studies, three papers made weak theory-practice links, briefly mentioning single concepts including goal setting, positive thinking, stress management, empowerment, and active listening (Dale et al., 2010; Davis et al., 2010; Faridi

et al., 2008).

Are Proposed Predictor Variables Measured Pre and Post Intervention with Validated Tools?

Predictor variables measured across the reviewed studies included outcome expectancies (Miller & Gutschall, 2009; Wu et al., 2011), diabetes knowledge (Miller & Gutschall, 2009; Hawkins, 2010; Sacco et al., 2009; Rosal, 2011), illness perceptions (Keogh et al., 2011), perceived stage of change (Moriyama et al., 2009), self regulation skills (Huisman, 2009), behavioural intentions and proactive coping (Thoolen et al., 2009), perceived family support (Keogh et al., 2011), stress management, problem solving and social resources (Toobert et al., 2007), perceived reinforcement for self-care, and awareness of the discrepancies between actual and desired goal related performance (Sacco et al., 2009). Self-efficacy was the most commonly measured predictor; only three studies did not measure self-efficacy (Davis et al., 2010; Huisman et al., 2009; Osborn, 2011). Most studies targeting self-efficacy, measured the construct pre and post intervention. In contrast, Glasgow et al (2006) employed their own self-efficacy measure within their intervention but this was not measured at outcome. Some authors, despite naming psychological concepts, did not measure proposed predictors (Davis et al., 2010; Osborn et al., 2011)

Most authors reported using previously validated tools to measure predictor variables. Three studied employed translated measures (Moriyama et al., 2009; Shi et al., 2010; Wu et al., 2011). A number of studies provided previously published Chronbach's alphas for the these tools (Hawkins, 2010; Huisman et al., 2009; Keogh et al., 2011; Lorig et al., 2009; Miller Gutschall, 2009; Sacco et al., 2009; Thoolen et a., 2009; Toobert et al., 2007), others also reported pre test Chronbach's alphas for their own samples (Sacco et al.,

Shi et al., 2010; Thoolen et al., 2009; Wu et al., 2011). Where Chronbach's alphas were reported, they lay between 0.61 and 0.94; suggesting that most tools achieved at least acceptable internal consistency.

In addition to using validated measures, some studies developed their own tools. Rosal et al (2011) developed their own tool to measure self-efficacy for diet and exercise, and provided the Chronbach's alpha for their sample (0.85). For their study Sacco et al. (2009) developed their own scales to measure perceived social support from health care professionals, perceived reinforcement for self-care behaviour, and awareness of self-care goals; reported Chronbach's alphas lay between 0.64 and 0.94, suggesting adequate internal consistency.

There was little overlap in the predictor measures used by the studies, for example, eight different measures of self-efficacy were employed across fourteen studies.

Table 4: Self Report Measures Employed by the Reviewed Papers

Self-report Measures	Studies Employing the Measure	Developers (as cited by authors)
Self-efficacy		
Diabetes Management Self-Efficacy Scale	Dale et al., 2009; Hawkins, 2010; Miller & Gutschall 2009	Sturt & Hearnshaw, 2003
Diabetes Management Self-efficacy Scale	Keogh et al., 2011; Shi et al., 2010; Wu et al., 2011 (the last two translated into Chinese)	van de Bijl, Poelgeest-Eeltink, & Shortridge-Baggett, 1999
The Self-efficacy Scale	Lorig et al., 2009	Lorig, Stewart, Ritter, Gonzalez, Laurent, & Lynch, 1996
Diabetes Empowerment Scale – Short Form (DES-SF)	Hawkins, 2010; Miller & Gutschall, 2009	Anderson, Fitzgerald, Gruppen, & Oh, 2003
The Multidimensional Diabetes Questionnaire Self-efficacy subscale (MDQ-SE)	Sacco et al., 2009	Talbot, Nouwen, Gingras, Gosselin, & Audet, 1997
General Self-Efficacy Scale (GSES) – Japanese version	Moriyama et al., 2009	Narita et al., 2001
Self-efficacy Questionnaire	Miller & Gutschall , 2009	Miller, Gutschall, & Lawrence, 2007
Sallis Self-efficacy for Diet and Exercise Behaviour (SSEDE)	Toobert et al., 2007	Sallis, Pinski, Grossman, Paterson, & Nader, 1998
Confidence in Overcoming Challenges to Self-care (COCSC)	Toobert el al 2007	Glasgow, Toobert & Gillett 2001
Other Predictor Variables		
Outcome Expectancy Questionnaire	Miller & Gutschall , 2009	Miller, Gutschall, & Lawrence, 2007
Perceived Therapeutic Effect Scale (Chinese version)	Wu et al., 2011	Shortridge-Baggett, 2001
The Brief Illness Perceptions Questionnaire	Keogh et al., 2011	Broadbent, Petrie, Main, & Weinman, 2006
Self Regulation Skills Battery	Huisman et al., 2009	Maes, Karoly, de Gutht, Ruehlman, & Heiser, 2006
The Proactive Competence Inventory	Thoolen et al., 2009	Bode, Ridder, & Bensing, 2006
Intentions measure	Thoolen et al., 2009	Fishbein & Ajzen, 1975
Reinforcement for Self-care	developed for study by Sacco et al., 2009	Developed by Authors
Awareness of Self-care Goals -	developed for study by Sacco et al., 2009	Developed by Authors
The Diabetes Knowledge Test (DKT)	Hawkins, 2010; Sacco et al., 2009	Fitzgerald et al., 1998
Audit of Diabetes Knowledge (ADKnowl)	Rosal et al., 2011	Speight & Bradley, 2001
Understanding Subscale of the Michigan Diabetes Research and Training Centre Diabetes Care Profile (MDRTDBCP)	Sacco et al., 2009	Michigan Diabetes Research and Training Centre
Social support		
Perceived Social Support from HCPs	Sacco et al., 2009	Developed by Authors
Diabetes Family Behaviour Checklist	Keogh et al., 2011	Schafer, McCaul & Glasgow, 1986

Self-report Measures	Studies Employing the Measure	Developers (as cited by authors)
Chronic Illness Resources Survey (CIRS)	Toobert et al., 2007	Glasgow, Stryker, Toobert, & Eakin, 2000
Psychosocial Outcomes		
WHO-QOL26 - Japanese Version (Quality of life measure)	Moriyama et al., 2009	World Health Organisation, 1998
Wellbeing Questionnaire	Keogh et al., 2011	Bradley, 2000
Centre for Epidemiologic Studies Depression Scale (CES-D)	Toobert el al 2007	Radloff, 1977
Diabetes Problem Solving Interview (DPSI)	Toobert et al., 2007	Toobert & Glasgow, 1991
Problem Areas in Diabetes Scale (PAID)	Dale, 2009	Polonsky et at., 1995
Revised Diabetes Distress Scale (DDS)	Glasgow et al., 2006; Toobert el al., 2007	Polonsky et al., 2005
The Patient Health Questionnaire (PHQ-9)	Glasgow et al., 2006; Sacco et al., 2009	Kroenke, Spitzer, & Williams, 2001
Perceived Stress Scale (PPS)	Toobert el al 2007	Cohen, Kamark, & Mermelstein, 1983
Self-care		
The Kristal Food Habits Questionnaire	Thoolen et al., 2009	Kristal, Shattuck, & Henry, 1990
The Dutch fat Consumption Questionnaire DFCQ	Thoolen et al., 2009	Assema, Brug, Kok, & Brants 1992
Medical Adherence Report Scale	Thoolen et al., 2009	Horne & Weinman, 1999
Summary of Diabetes Self-care Activities Questionnaire (1994)	Sacco et al., 2009	Toobert and Glasgow 1994
Summary of Diabetes Self-Care Activities	Keogh et al., 2011; Shi et al., 2010; Wu et al., 2011 (the last two translated into Chinese)	Toobert, Hampson, & Glasgow, 2000
Minnesota Nutrition Data System For Research 2005 – 24 hour-recall Structured Interview (NDS-R)	Miller & Gutschall, 2009	Nutrition Coordinating Centre, University of Minnesota (2005)
The Semi-Qualitative Food Frequency Questionnaire (FFQ)	Toobert et al., 2007	Fred Hutchinson Cancer Research Centre
Symptoms		
Diabetes Symptom Checklist (DSC)	Sacco et al., 2009	Grootenhuis et al., 1994

Are Findings Discussed in the Light of Theory?

Glasgow et al. (2006) did not employ self-efficacy as an outcome measure and their findings were not discussed within the SCT framework. This was despite the mention of Social-Cognitive Theory in the abstract and an appropriate use of self-efficacy and motivational interviewing within their intervention. Similarly, Toobert et al. (2009) measured some constructs relevant to the SCT at baseline, outcome and follow-up. They also employed intervention techniques that could theoretically influence behaviour change, but made no attempt to interpret their findings in the light of theory or investigate the predictive value of, for example, self-efficacy in relation to behaviour change.

In contrast, Rosal et al. (2011) found reductions in HbA1c (significant treatment effect) to be associated with increased self-efficacy and diabetes knowledge; they concluded that their findings support the utility of the SCT approach to diabetes self-management. Shi et al. (2010) found improved glycaemic control among their treatment group and put this down to intervention strategies that targeted self-efficacy, but they did not mention the SCT in their conclusion. Sacco et al. (2009) found mediation effects for (a) self-efficacy on depression, (b) reinforcement on exercise activity, and (c) goal awareness on foot care. They concluded that increases in self-efficacy, goal awareness and the experience of praise, supported mood and motivation to make positive behaviour change. The authors did not, however, discuss these findings in terms of the larger theoretical frameworks. Hawkins (2010) did link theoretical frameworks applied (SCT and TTM) to her findings. For example, an interaction effect was found within the treatment group such that self-efficacy was associated with greater improvement in glycaemic control. Thus the proposed association

between self-efficacy and glycaemic control was tested and found. It is surprising, though, that key TTM constructs such as stage of change or cost/benefits analysis were not measured or discussed.

Moriyama et al. (2009) clearly interpret their findings within theoretical hypotheses; for example, they link improvements in self-efficacy from three months onwards with a similar pattern of improvement in glycaemic control and body weight for the intervention group. Similarly, Keogh et al. (2011) attribute their positive findings to demonstrated improvements in participants' illness representations (beliefs) about how much personal and treatment control they have, and an increased sense of understanding diabetes (coherence).

Three studies made no mention of theory in their discussions (e.g., Faridi et al., 2008; Lorig et al., 2009). Others simply discuss whether an intervention, based on a named theory, was effective (Osborn et al., 2011).

Is Theory Evaluated?

Only four papers made sufficient mention of the proposed mechanisms of behaviour change to be of use in evaluating the clinical validity of theory. Although Moriyama et al. (2009) did not explicitly evaluate the TTM in the light of their findings, they did provide sufficient information for the reader to consider the how the TTM explains their findings. They measured stage of change for diet and exercise at 3, 6, 9, and 12 months during the intervention. In addition to incremental improvements in these two behaviours for the intervention group over the control, the authors noted that intervention participants' stage of change moved from a predominantly maintenance to a predominantly action phase, suggesting they were increasing their goal setting behaviour. In contrast the control group

participants remained predominantly in maintenance.

Thoolen et al. (2009) used their results to compare the utility of the SCT and Self-Regulation frameworks; concluding that, while self-efficacy and motivation (SCT) predicted behavioural intentions, proactive coping was a better predictor of sustained change (SR).

Finally, when no treatment effects were found Huisman et al. (2009) pooled their sample and conducted post hoc analyses that showed higher baseline self regulation scores were associated with better glycaemic control, across both groups, at each interval. They suggest that SR interventions may have improved self regulation skills only in patients who already possessed such skills and hypothesised that aspects of self-regulation could be trait in nature (i.e., people are either self regulators verses external regulators) and therefore resistant to self-regulation interventions. They do not conclude this is a limitation of the model, rather they suggest that future research should employ an assessment to identify "self regulators" who might benefit from SR approaches.

Interventionists

Most papers employed more than one type of interventionist (i.e., those providing the intervention), but only three papers reported psychology input (Huisman et al., 2009; Keogh et al., 2011; Sacco et al., 2009). The first two studies were led by a psychologist while the latter employed trained coaches, supervised by a Psychologist. Rosal et al. (2011) do not report which professionals delivered their intervention but the first author is a clinical psychologist. The remaining papers employed dieticians, specialist nurses, certified diabetes educators, health coaches, and exercise physiologists, a medical assistant (Osborn et al. 2011) and peers (Dale et al., 2009; Lorig et al., 2009; Rosal et al., 2011). Interventionists in

four of the studies were trained in motivational interviewing (MI). One study described this training as self-instructional (Glasgow et al, 2006), another described that MI was one element of a 40-hour training given to the medical assistant who delivered their intervention (Osborn et al 2011). In the majority of cases, professionals involved in administering interventions, also administered usual care among control groups.

Intervention Mode/Medium

The studies employed a number of different modes of intervention such as group programmes (four studies), individual contact, and printed material. Most often these modes were used in combination. The size of the intervention input varied considerably. Group programmes ranged from four group sessions sandwiched between two individual sessions (Thoolen et al, 2009) to weekly group sessions (4-hour-long) for 6 months (Toobert el al, 2007). Similarly, individual contacts ranged from one individual session plus telephone contact as required (Glasgow et al, 2006) to weekly contact for three months (Hawkins, 2010). Most interventions included homework as a means of behaviour change, usually in the form of goal monitoring.

Often interventions employed technology such as telephones (Dale et al. 2009; Glasgow et al., 2006; Moriyama et al, 2009), videophone (Davies et al., 2010; Hawkins, 2010), and computer programs (Glasgow et al) to reach and engage participants in cost effective ways. Faridi et al (2008) piloted a mobile phone system that transmitted blood sugar readings and physical activity information directly to interventionists, facilitating tailored feedback via text.

Dietary Self-care Measurement and Outcomes

Most of the studies reviewed took multiple measures of diet behaviour. Table 4 presents a summary of outcome variables and effects found. Clinical measures included glycosylated haemoglobin, blood lipid levels, fasting blood sugar glycaemic index, and glycaemic load. Biometric measures included body mass index, body weight, and waist circumference. Self-report measures included various research developed diaries, but most used previously validated inventories to measure fat, fruit and vegetable, and carbohydrate consumption. Sacco et al. (2009) asked participants to complete the Diabetes Self-care Activities Questionnaire (Toobert & Glasgow, 1994) which includes 5 specific diabetes diet-related items. Osborn et al (2011) employed the revised version of the Summary of Diabetes Self-Care Activities (SDSCA; Toobert, Hampson and Glasgow, 2000). Shi et al. (2010) and Wu et al. (2011) also employed the SDSCA, translated into Chinese.

Twelve of the seventeen papers found at least one treatment effect related to dietary self-care. The most commonly reported improvements were in glycaemic control (Davis et al., 2010; Hawkins, 2010; Keogh et al., 2011; Moriyama et al., 2009; Osborn et al., 2011; Rosal et al., 2011), and self-reported dietary self-care (Glasgow et al., 2006; Lorig et al., 2009; Moriyama et al., 2009; Osborn et al., 2011; Rosal et al., 2011; Shi et al., 2010; Thoolen et al., 2009; Toobert et al., 2007). Treatment effects were also found for glycaemic index (Miller & Gutschall, 2009), cholesterol level (Davis et al. 2010) and body weight (Glasgow et al., 2006; Moriyama et al., 2009; Rosal et al., 2011). Of the eight studies measuring BMI, only two studies reported a significant treatment effect (Rosal et al., 2011; Thoolen et al., 2009).

Shi et al (2010) reported sustained treatment effects for self reported dietary self-care at 4 months follow up. Toobert et al. (2007) showed that improvements in dietary fat intake were maintained at 12 and 24 month post intervention (in comparison to their control group). Miller et al. (2009), having employed an immediate and delayed treatment group, reported sustained improvement in the immediate treatment group at 9 months follow-up (though without a control group comparison). Similarly, Lorig et al. (2009), having failed to find a treatment effect for glycaemic control, reported sustained improvements in self-efficacy and some self-care behaviours including healthy eating at 12 months follow-up.

A number of authors offered explanations for negative results. Dale et al. (2009) reported improvements in glycaemic control and cholesterol levels for the intervention and control groups but no between-group differences. They account for this by suggesting that [British] government-backed initiatives in diabetes care, at the time of the study, meant "usual care" was very comprehensive and thus similar to the support offered to the intervention group. Huisman et al (2009) reported that, although no significant treatment effects were found, high self-regulators across the whole sample had better glycaemic control than low self-regulators. Glasgow et al (2006) failed to find improvements in fruit and vegetable consumption despite impressive treatment effects for dietary fat consumption and exercise. The authors explain that, because fruit and vegetable consumption was infrequently chosen as a self-selected goal, the controlled comparison may have lacked sufficient power to detect any treatment effect.

Table 5: Showing Outcome Variables by Article with Findings.

Measured Variables	Dale et al., 2009	Davis et al., 2010	Faridi Et al.,2008	Glasgow et al., 2006	Hawkins, 2010	Huisman et al., 2009	Keogh et al., 2011	Lorig et al., 2009	Miller & Gutschall, 2009	Moriyama et al., 2009	Osborn et al., 2011	Rosal et al., 2011	Sacco et al., 2009	Shi et al., 2010	Thoolen et al., 2009	Toobert et al., 2007	Wu et al., 2011
Predictors Variables																	
Self-efficacy	○		◊		●		◊	●	●	◊		●	●	●	●	●●	●
Empowerment									●								
Outcome Expectations									●								●
Diabetes Knowledge					◊				●			●	●	◊			
Family Support							◊										
Perceived support from HCPs													●				
Patient Activation (knowledge, skill, and confidence)								●									
Proactive Competence and Behaviour															●		
Stage of change (diet & exercise)										●							
Illness Perceptions							●										
Dietary Intention															●		
Exercise Intention															●		
Medication Intention															○		
Problem Solving																●	
Psychosocial Outcomes																	
Self Regulation Skills						□											
Wellbeing							◊										
Diabetes Distress	○																
Depression				○				●					●			○	
Quality of Life				○		○				●						○	
Stress Management																●	
Goal Attainment															●		
Social Resources																●	

Measured Variables	Dale et al., 2009	Davis et al., 2010	Faridi Et al .,2008	Glasgow et al ., 2006	Hawkins, 2010	Huisman et al ., 2009	Keogh et al., 2011	Lorig et al., 2009	Miller & Gutschall, 2009	Moriyama et al., 2009	Osborn et al., 2011	Rosal et al ., 2011	Sacco et al ., 2009	Shi et al ., 2010	Thoolen et al., 2009	Toobert et al., 2007	Wu et al., 2011
Communication with Physicians								●									
Dietary Related Outcomes																	
Glycaemic Index									●								
Fasting Blood Sugar									●								
Glycaemic Control (GC)	HbA1c ○	GHb ●	HbA1c ○	HbA1c ○	HbA1c ◊	HbA1c ○	A1c ●	A1c ○		HbA1c ◊	HbA1c ◊	HbA1c ●	A1c ○				
Cholesterol		●		○	○					○		○					
Dietary Fat				●			○								●		
Fruit & Veg Intake				○			○										
Dietary Intake						○		●	●		◊	●	●		●	●	
BMI		○	○		○	○	○					●	○		●		
Body Weight			○	●		○		○		◊		●					
Waist Circumference		○								◊		●					
Other Outcomes																	
Exercise			○			○		●				○			●	●	
Foot Care													●				
Diabetes Self-care							◊				◊			●	●		●
Taking Medication												©			●		
Blood Self-Monitoring							○					●	○				
Symptoms of hyperglycaemia								●									
Albumin-to-Creatinin		○															
Blood Pressure		○	○		○		○			○							
Fatigue								●									
Diabetes Related Emergency Health Care																	○

● = significant between group difference in favour of intervention; ◊ = significant within group improvement for intervention group but not control; ○ = no between group differences;

© significant improvements found in both groups; □ = no comparison made.

Other Intervention Targets and Outcomes

In addition to dietary self-care, all of the studies targeted additional outcome variables. These are detailed in Table 5. Across the studies, no treatment effects were reported for clinical outcomes such as blood pressure, and number of diabetes related emergency health care attendances. Effects were found, however for improvement in reported fatigue and hyperglycaemic symptoms (Lorig et al., 2010). Reported treatment effects for behavioural outcomes included physical activity (Huisman et al., 2009; Lorig et al., 2009; Moriyama et al., 2009; Sacco et al., 2009; Thoolen et al., 2009; Toobert et al., 2007; Wu et al., 2011) medication management (Thoolen et al., 2009), communicating with physicians (Lorig et al., 2009), glucose monitoring (Rosal et al.,2011), stress-management practices (Toobert et al., 2007), reading food labels (Lorig et al., 2009; Moriyama et al., 2009; Osborn et al., 2011), foot care and eye care (Sacco et al., 2009). As regards psychosocial outcomes, self-efficacy was the most commonly found treatment effect with only one of the thirteen studies, measuring SE, failing to find a treatment effect (Dale et al., 2009). Other psychosocial treatment effects were found for diabetes knowledge (Hawkins, 2010; Miller et al., 2009; Rosal et al.,2011; Sacco et al., 2009), psychological wellbeing (Keogh et al., 2011), depression (Lorig et al., 2009; Sacco et al, 2009) and social support (Keogh et al, 2001; Sacco et al., 2009; Toobert et al., 2007).

Discussion

The aims of this review were to evaluate the extent to which recent studies employing psychological theory to promote dietary self-care among adults with type 2 diabetes were, a) truly theory based and b) effective. Seventeen randomised control trials

conducted since 2006 were retrieved for review. One paper was retrieved in each year between 2006 and 2008, seven studies were retrieved in 2009, three in 2010, and four in 2011. This suggests that the recent call to underpin interventions with a sound understanding of behaviour change has been heeded (Norris et al, 2001; Heinrich & Schaper, 2010).

In most cases sufficient information was available to assess the quality of the studies, and most made reasonable attempts to avoid bias and target at-risk samples. Studies varied greatly in sample size and therefore power to detect a meaningful treatment effect with only four studies achieving at least one hundred participants per arm (Glasgow et al., 2006; Lorig et al., 2009; Rosal et al., 2011; Toobert et al., 2007).

The theory coding system (TCS), provided by Michie and Prestwich (2010), was employed to assess the extent to which psychological theory was operationalised and tested within the reviewed studies. The most widely used theory among authors was the Social-Cognitive Theory (SCT). Other theories named included the Transtheoretical Model (TTM), the Self Regulatory Theory (SR), the Health Belief Model (HBM), and the Information-Motivation-Behavioural Skills Model (IMB). While one study measured intentions, the Theory of Planned behaviour was not represented in this sample of research studies. Self-efficacy was the most commonly named psychological construct, and the only construct named in three of the studies (Faridi et al., 2008; Lorig et al., 2009; Shi et al., 2010). Only four studies targeted all constructs relevant to their named theory (Miller & Gutschall, 2009; Moriyama et al., 2010; Keogh, 2011; Osborn, 2011), while most of the others targeted at least one relevant construct.

Seven studies explicitly described how theory informed elements within their interventions (Huisman et al.,2009; Keogh, 2011; Miller & Gutschall, 2009; Moriyama et al., 2010; Osborn et al., 2011; Rosal et al., 2011; Shi et al., 2010; Thoolen et al., 2009 and Wu et al., 2011). Some other studies described their interventions in terms of smaller concepts such as motivational interviewing without reference to the larger theoretical frameworks they had introduced (Hawkins, 2010; Sacco et al., 2009; Shi et al., 2010). Most other studies described methods that reflected theory but this was not made explicit. Finally, three studies failed to make any clear theory-practice links (Dale et al., 2009; Davis et al., 2010; Faridi et al., 2008).

In the majority of cases predictor variables were measured with validated tools but there was little overlap among the tools used. A lack of standardised measurement limits the conclusions that can be drawn from reviews (Gary et al., 2003). While a call for comprehensive theory driven approaches will require the development of new tools to measure currently untargeted constructs, the field may benefit from using validated and widely used measures when available. There was evidence of this approach being taken in relation to outcome measures, for example, the Summary of Diabetes Self-Care Activities (Toobert, Hampson, & Glasgow, 2000) was employed by three studies and had been translated into Chinese.

Less than half of the reviewed papers described findings in terms of theory (Hawkins, 2010; Huisman et al., 2009; Keogh et al., 2011; Moriyama et al., 2009; Rosal et al., 2011; Thoolen et al., 2009), and only four made any attempt to evaluate the clinical utility of theory in the light of their findings (Huisman et al., 2009; Moriyama et al., 2009; Rosal et al.,

2011; Thoolen et al; 2009). This suggests that, while most of the reviewed studies made reasonable attempts to apply and evaluate the efficacy of interventions that were based on psychological theory, very few paid attention to testing theory.

Individuals conducting interventions were often nurses, dieticians and sometimes peers, but generally not psychologists. Very little information was provided about training and psychology input was reported in only four studies.

The reviewed studies were reasonably effective in promoting dietary self-care, in the short term, and this reflects previous review findings (Gary et al., 2003; Ellis et al., 2004; Liang et al., 2011; Norris et al., 2001; Steed et al., 2003). Most achieved at least one treatment effect for diet behaviour, although in six studies this was self reported change (Glasgow et al., 2006; Lorig et al., 2009; Miller & Gutschall, 2009; Thoolen et al., 2009; Toobert et al., 2007 Shi., 2010). Glycaemic control was the most frequently targeted and achieved treatment effect (Davis et al., 2010; Hawkins, 2010; Keogh et al., 2011; Moriyama et al., 2009; Osborn et al., 2011; Rosal et al., 2011). This is an indirect dietary measure but more objective than self reported dietary intake, however, it does not reflect all of the dietary priorities in T2DM. Weight loss is also required to reduce CHD risk profile. Although measured frequently BMI rarely improved, suggesting glycaemic control and weight loss behaviours may have different predictors and may need to be targeted differently within future interventions.

Overall, the reported effects of the reviewed self-management interventions on dietary self-care were not clinically trivial but they are similar to the treatments effects reported for intervention studies that did not claim to apply psychological theory (e.g., Scain,

Friedman, & Gross, 2009). As with the predictor variables, a number of different assessment tools were employed across the studies. Given the lack of a common metric and the variable application of theory it has not been possible to assess whether one theory was more effective than any other.

Across the studies most of the outcome variables relevant to effective self-management of T2DM were targeted, such as dietary self-care, physical activity, self-monitoring of blood glucose, eye and foot care. The studies employed a variety of intervention formats including individual sessions, groups, family involvement, printed material, and homework tasks. Most authors explicitly avoided didactic formats. Modes of intervention also varied and a number of creative ways of accessing and engaging people with the use of technology have been introduced. These may provide good opportunities to effectively and efficiently apply and evaluate the clinical validity of psychological theory in future.

In contrast to the findings of a previous review (Povey & Clark-Carter (2007), the reviewed studies generally offered clear information about interventions, despite any lack of theory-practice links. Previous reviewers have also suggested that the variable nature of intervention formats and mediums make it difficult to generalise conclusions about the state of the research field (Gary et al., 2003). The studies reviewed here generally gave good justification for the intervention strategies they employed (e.g., to engage difficult to reach samples, to provide cost effective support, or to provide culturally valid interventions). With more standardised measurement and clear hypotheses, it may be possible to retain variety within self-management interventions for T2DM and still facilitate evaluation and

improvement of provision.

Review Limitations

Only studies claiming theoretic basis or mentioning a psychological construct were included in this review. Authors not claiming a psychological basis for their studies during this period may have conducted studies that operationalised aspects of theory within their interventions but these were excluded. Diabetes self-management research is a massive and heavily reviewed field. The search strategy for current review employed three large data bases (those most cited by previous reviewers). However, given the size of the research field it remains possible that this strategy did not capture every paper meeting our inclusion criteria.

Research Implications

This review has highlighted a need to design, conduct and evaluate interventions for T2DM with clearer reference to psychological theory. It will be important, in future research, to state clear theoretical hypothesis around the psychological mechanisms for predicted treatment effects and measure predictor constructs with common validated tools. Given the modest findings found among the reviewed papers future research will need to apply theory in testable ways in order to contribute to the refinement of theory and practice. The theory coding system (Michie & Prestwich, 2010) offers a clear framework for doing this.

Clinical Implications

Increased input from psychologists may support efforts to explicitly apply psychological theory within future self-management interventions, and interpret findings in

relation psychological theory. In this way theory-practice links may be strengthened, illuminating the psychological factors that are responsible for current treatment effects and hopefully leading to improved treatment effects over time. This input should include intervention design, protocols, and joint delivery, in addition to training and supervision.

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Investigating the Influence of Illness Representations on Health and Dietary Outcomes for Coeliac Disease.

Abstract

Objectives

Coeliac Disease (CD) is a common chronic autoimmune disorder characterised by sensitivity to gluten. This study investigated the relationships between CD illness representations, coping, self-efficacy, health related quality of life, wellbeing, psychological distress and dietary self-care (following a gluten free diet) among adults with coeliac disease.

Design

A questionnaire-based correlational design was used to investigate hypothesised relationships.

Methods

Ninety six adults with CD, recruited through dietician clinics, completed a single booklet of questionnaires about their beliefs, experiences and behaviour in relation to their CD. In addition serology (CD antibody levels) and clinician rated levels of dietary self-care (both taken within one month of participation) were employed as additional measures of behaviour.

Results

Results of regression analyses showed that some aspects of illness representation were related to some psychosocial but not levels of dietary self-care (which was generally high among the sample). Specifically, consequence beliefs were associated with quality of life, psychological distress, and wellbeing. Emotional representations were associated with quality of life and psychological distress.

Conclusions

Illness representations may be useful in explaining psychosocial outcomes for CD, but more research would be needed to assess whether they are useful in explaining dietary behaviour among this population. Findings related to coping and self-efficacy are also discussed.

Introduction

Coeliac disease (CD) is a common chronic autoimmune disorder of the small intestine which features a permanent hypersensitivity to certain amino acids (gluten) found in wheat, barley, and rye (Thompson, Dennis, Higgins, Lee & Sharrett, 2005). In CD the ingestion of gluten causes the body's immune system to react and the small intestine to become inflamed. Repeated inflammation causes significant damage to the small intestinal wall such that the tiny finger-like projections (villi) that line the small bowel become truncated and appear flattened under a microscope (McGough & Cummings, 2005). This can significantly reduce the surface area available to absorb vital nutrients. Left untreated, individuals experience a range of symptoms associated with (a) abdominal inflammation such as pain and bloating; and (b) the malabsorption of iron, calcium and fibre causing conditions such as anaemia, osteoporosis, weight loss and fatigue (Thompson et al 2005). People with CD are also predisposed to serious health conditions including type 1 diabetes, infertility, gastrointestinal cancer (Jones, 2007), and some rare neurological disorders (McGough & Cummings, 2005). Diagnosis is through intestinal biopsy and blood test (for coeliac antibodies). Most people receive a diagnosis after experiencing gastroenterological symptoms, however, an increasing number of people with asymptomatic (silent) CD learn they have CD following unrelated medical investigations (Hall, Rubin, & Charnock, 2010).

The condition is very effectively managed by a life-long gluten-free diet (GFD). This, however, is experienced by some as restrictive. Gluten is a widely used and difficult ingredient to avoid, however, strict dietary self-care requires that no gluten is ingested (Lee & Newman, 2003). Common foods that contain gluten include most bakery products, sauces

and beer. In a survey by Lee and Newman (2003) most respondents (90%) thought of themselves as healthy, but also reported that gluten-free eating impacted negatively on dining out (86%), travelling (82%) and family life (67%). In general, more women than men endorsed negative experiences from adhering to a GFD. Sverker, Hensing, & Hallert (2005) conducted interviews with 43 people with CD who discussed three key areas of concern. These included the emotional response to their condition, social relationships and day-to-day management of their condition. Similarly, Zarkadas et al (2006) surveyed 2681 adult Canadians (75% were women) with CD. Respondents reported avoiding restaurants and travel, worrying when dining at friends' houses and not being invited for meals because of their food restrictions. Quantitative evidence relating to the impact of a GFD on quality of life (QoL) has been mixed (Roos, Karner & Hallert, 2006), but a number of recent studies have shown reduced health related quality of life (HRQOL) among CD populations (Häuser, Gold, Stein, Caspary & Stallmach, 2006; Sverker, Östlund, Hallert, & Hensing, 2009), particularly among women (e.g., Hallert, Sandlund & Broqvist, 2003). The dilemmas associated with having CD have also been found to impact on family members (Sverker et al 2007). Casellas et al. (2008) found that health related quality of life was reduced among newly diagnosed people with CD following a normal diet, while a sample following a GFD had higher levels of health related quality of life (close to that shown in a non-CD sample).

Most research into CD to date has focused on biomedical aetiology and treatments, but a growing body of psychosocial research has found higher prevalence of affective disorders (major depressive, dysthymic, panic and adjustment disorders) among those with CD than controls (Ciacci, Lavarone, Mazzacca, & De Rosa 1998; Ludvigsson, Reutfors, Ösby, Ekbom, & Montgomery, 2007). A psychosocial explanation of depression in CD credits the

influence of uncomfortable symptoms and a restrictive diet on QoL and wellbeing as evidenced across a number of studies. In contrast, a purely biological approach attributes depression to the malabsorption of nutrients that support mental health (Carter et al, 2003) or a co-existing tendency towards thyroid dysfunction (Carta et al, 2002). It has, however, been established that lower QoL and depression are associated with poorer dietary self-management (Addolorato, Stefanini, Capristo et al, 1996), possibly implicating both the biological and psycho-social pathways. Clearly more evidence is needed to illuminate the biopsychosocial interactions that influence the emotional impact, and self-management, of CD.

Theoretical frameworks from psychology might help to make sense of the influences on outcomes in terms of psychosocial wellbeing and dietary self-management. In particular, Leventhal's Common Sense Model of illness representations (CSM; Leventhal, Meyer, & Nerenz, 1980) proposes that individuals attempt to make sense of symptoms, health threats and illness by means of cognitive representations (based on pre-existing knowledge or schemas) and that these representations influence the selection and performance of strategies to cope with the illness (e.g., managing a gluten free diet). Self regulation is a dynamic process in which feedback about performance (e.g., how well they are managing their GFD) can also influence how the individual understands (represents) their condition. Early research identified five main components of individuals' illness representations. These are: (a) identity (the label of the illness and the symptoms the person views as being part of the condition); (b) cause (personal ideas about cause which may include simple single causes or more complex causal models); (c) time-line (how long the patient believes the illness will last, categorised into acute, chronic or episodic); (d) consequences (expected effects and

outcome of the illness); and (e) cure or controllability (how the patient believes s/he will recover from, or control, the illness) (Leventhal, Nerenz & Steele, 1984: Leventhal et al., 1997). This model has recently been extended to include two further components that take account of the individual's emotional response to the condition and the extent to which they can make coherent sense of their illness (Moss-Morris et al., 2002). These illness perceptions have been measured using the Illness Perception Questionnaire (IPQ; Weinman, Petrie, Moss-Morris, & Horne, 1996), and the revised IPQ (IPQ-R; Moss-Morris et al., 2002). The model has been useful in explaining psychosocial outcomes across a number of health conditions such as breast cancer, chronic fatigue syndrome and myocardial infarction (Petrie & Weinman, 1997).

Hagger and Orbell (2003) used meta-analytical techniques to review 43 studies that applied Leventhal's Commonsense Model (CSM) of illness representations to predict health outcomes across a range of 22 health conditions that require specific self-management strategies such as diabetes, asthma and irritable bowel syndrome. Using the data compiled for the meta-analysis, the authors then tested a general hypothesis that illness representations would be related to coping strategies and health outcomes. Illness representations were found to relate to coping; specifically perceptions of high control were associated with active coping behaviours and reappraisal of the illness. Conversely, strong perceptions of illness identity were directly associated with avoidant coping (e.g. denial) and higher emotional expression. Illness representations were also found to relate directly to some outcomes. Perceptions of fewer consequences and weaker illness identity were related to better outcomes in term of functioning and psychological adjustment (wellbeing and vitality).

Illness representations have been usefully applied to conditions with dietary implications such as diabetes (Searl, Norman, Thompson & Vedhara, 2007), irritable bowel syndrome (Rutter & Rutter, 2002) and acute inflammatory bowel disease (Parry, Corbett, Barton, & Welfare, 2003). Few studies have looked at how illness representations might relate to coping, HRQoL and emotional adjustment among people with CD. To the author's knowledge, Ford, Howard and Oyebode (in press) was the first paper to apply illness representations to inform an understanding of outcomes among a community sample of adults with CD. Ford et al found that strong beliefs in a cyclical timeline for CD was associated with lower self-efficacy, health related quality of life, and psychological wellbeing. Strong beliefs in personal control and illness coherence were related to higher self-efficacy for sticking to a gluten free diet. In contrast, strong beliefs in serious consequences and strong emotional representations were related to lower self-efficacy for a GFD. Self-efficacy is defined as a person's belief in their own ability to carry out meaningful behavioural goals (Bandura, 1977) and was found to be an important positive influence on dietary self-care (Ford et al., in press). These findings suggest that, for conditions requiring strict dietary self-management, more adaptive illness representations are those which reflect lower perceptions of identity, cyclical timeline, emotional response and serious consequences, and stronger beliefs in personal control and illness coherence.

The current study sits alongside a larger project, funded by Coeliac UK, which looked at a community sample of people across the UK living with CD. The current research study supplemented this by recruiting a clinical sample through gastroenterology services. A general hypothesis was forwarded that illness representations would be associated with health outcomes for a sample of medically diagnosed adults with CD. Specific hypotheses

were that (a) strong personal control beliefs, a greater sense of illness coherence, and lower emotional representations would be associated with better psychosocial and behavioural outcomes (i.e., lower psychological distress and better health related quality of life, wellbeing, self-efficacy and dietary self-care; and (b) in contrast, strong illness identity (perceived symptoms), and strongly held beliefs in severe consequences and a chronic or cyclical timeline would be associated with poorer health outcomes (i.e., increased psychological distress and reduced HRQoL, wellbeing, self-efficacy and dietary self-care).

Finally coping is an important construct within the concept of illness representations and has been variably found to mediate the influence of illness representations on outcomes across a number of health conditions (Hagger & Orbell, 2003; Edgar & Skinner, 2003). Thus an additional aim of this study was to investigate the relationships between coping, illness representations and outcomes. Since there were no previous findings to guide specific hypotheses relating to coping in CD, this was an exploratory investigation.

Method

Design

A questionnaire-based correlational design was used to investigate the relationships between self-reported measures of illness representations, coping, psychosocial impact, and dietary self-management of a GFD among adults with CD. Adults with CD were invited to complete a single booklet of validated questionnaires. In addition to self reported data, the participants' most recent blood test results (for coeliac antibodies) were employed as a biological marker of recent gluten ingestion. In order to capture clinical expertise in interpreting these blood results we also asked the participants' dietician to rate their dietary

self-management. A sample size calculation, using (GPower 3.1) suggested a sample size of between 118-131 sets of useable data would be required to detect a medium effect size (f2) of 0.15, with a power of 0.8, at a significance level (alpha) of 0.05. Thus a target sample size of 150 was set.

Ethical approval was obtained from the University of Birmingham, School of Psychology Research Ethics Committee and the Derbyshire NHS Research Ethics Committee (see Appendices C & D). NHS Research and Development approval was achieved from participating NHS Trusts.

Participants

One hundred and eleven adults with medically diagnosed CD were consecutively recruited via two CD services located within the East Midlands (site 1) and West Midlands (site 2).

Participants were over 18 years, had sufficient mental capacity to give informed consent, and had sufficient comprehension of the English language to understand the questionnaire items. They had been diagnosed with CD for at least one year. Exclusion criteria included any co-morbid condition that impacts on dietary management or behaviour including diabetes, nut allergies, anorexia, and other gastroenterology disorders.

Procedure

Recruitment at Clinics

At site 1, individuals fulfilling the inclusion criteria received, along with their routine annual review appointment letter, an invitation to take part in the proposed study. Also

enclosed was a comprehensive information sheet that 1) explained what participation would entail, 2) clearly stated that participation was voluntary and that a decision not to participate would not impact on the care they received, and 3) included the contact details for the researcher and her supervisors should individuals have any queries or concerns. Appointment letters were sent out approximately 4-6 week prior to the appointment day to give participants sufficient to consider participation.

On the day of their appointment the attending dietician impartially asked whether the individual would like to participate or have further information about the study. People who did not wish to participate were thanked for their time and told they need not meet the researcher. People expressing an interest in taking part were escorted through to a second room where I was available to answer any further queries. If an individual was then happy to take part, I took informed consent. If individuals chose not to take part, they were thanked for their time.

Consented participants then received a booklet of questionnaires which took approximately 30 minutes to complete. There was somewhere quiet within the clinic where they could do this and the researcher remained available should they have questions while completing the questionnaires. Participants then returned the completed questionnaires to the researcher. Participants were encouraged to complete the questionnaires in clinic but pre-paid self-addressed envelopes were provided should they prefer to take the questionnaires home. If questionnaires were not returned within two weeks one follow-up contact was made, using the contact details given on the consent form. No further contact was made if questionnaires were not returned after follow-up contact.

Consent was also given for the release of two coeliac antibodies blood results, the most recent (usually taken on the day of the appointment) and the one previous to this. In addition to this, consent allowed for the dietician to interpret the blood results in conjunction with their consultation and rate each participant's gluten free dietary self-management on a scale from 0-5, where 5 represented excellent dietary self-management.

Recruitment by Mailshot

As there was no specific coeliac disease clinic at study site 2, the invitations, information sheets and questionnaires, complete with consent forms, were posted out to people identified by their clinicians as meeting the inclusion criteria. This pack included a covering letter from their clinician clearly stating that the service had no vested interest in their participation; that participation was voluntary; and that non-participation would not affect the care they received. Pre-paid self-addressed envelopes were provided for those wishing to participate to return the completed questionnaires. No attempt was made to contact these individuals if they chose not to return the questionnaires.

Measures

The single booklet of measures given to participants asked for general demographic information together with information about diagnosis. In addition the booklet contained the following measures, (a full list of items by scale is available in Appendix E):

1. The Revised Illness Perception Questionnaire (IPQ-R; Moss-Morris, Weinman, Petrie, Horne, Cameron & Buick, 2002). This measure comprises 8 scales and 58 items in total. The first scale (Illness identity) asks participants to answer yes or no to experiencing 20 listed

physical symptoms (e.g. abdominal pain, bloating, heartburn). Each participant's identity score is the number of symptoms experienced and attributed to CD. The other 7 scales ask participants to rate (on a 5-point Likert scale) the extent to which they agree or disagree with given statements. These scales are designed to measure the participants' illness perceptions in relation to each component of illness representation. The timeline (acute, chronic) scale comprises 6 items (e.g. "My illness will last a short time"). The consequences scale comprises 6 items (e.g., "My CD is a serious condition"). The personal control scale comprises 6 items (e.g., "I have the power to influence my CD"). The treatment control scale comprises 5 items (e.g., "My gluten free diet can control my CD"). The illness coherence scale comprises 5 items (e.g., I have a clear picture or understanding of my CD"). The timeline (cyclical) scale comprises 4 items (e.g., "my symptoms come and go in cycles"). Finally, the emotional representation scale comprises 6 items (e.g., "My CD makes me feel angry"). The authors report good internal consistency across the scales (Cronbach's @, 0.79 to 0.89).

2. Following your Gluten-Free Diet for CD (Dietary Self-efficacy). In the absence of a standardised measure of gluten-free dietary self-efficacy a measure was developed based on previous literature on general dietary self-management (such as Glasgow, McPaul & Schafer,1989; Senecal, Nouwen, & White, 2000; and Nouwen, Law, Hussain & Napier, 2009). Dr Jane Petty (University of Birmingham) made adaptations following pilot studies employing focus group methodology to tailor the items specifically to managing a gluten free diet (GFD). The resulting measure is a 34- item questionnaire. Each item asks participants to rate (on a 0-10 Likert scale) how confident they are in their ability to manage a GFD in specific situations that are common barriers to CD dietary self-management (e.g., "when I am in a

hotel").

3. The Coeliac Disease Questionnaire – Health Related Quality of Life (CDQ-HRQoL; Hauser, Gold, Stallmach, Caspary,& Stein, 2007). This is a 28-item measure with 4 scales, each employing a 7-point Likert scale response mode. The questionnaire instructs participants to consider the last two weeks, and each scale asks about an aspect of HRQoL. The gastrointestinal symptoms scale comprises 7 items (e.g., "How often did you suffer from bloating or flatulence?"). The emotional wellbeing scale comprises 7 items (e.g., "How often have you felt relaxed and free of tension?"). The social restrictions scale comprises 7 items (e.g., "How often did you feel isolated or excluded by others due to your CD?"). Finally the Disease-related worries scale comprised 7 items (e.g., "How often did you worry that your CD was diagnosed too late?"). In each case participants are asked to indicate an answer ranging from, for example, "none of the time" to "all of the time". Scale scores range from 7-49, and total HRQoL scores range from 7-196. Authors report excellent internal consistency, with Cronbach's alphas ranging from 0.80 to 0.91 across the scales.

4. The Psychological General Wellbeing Index-Short (PGWB-S; Grossi et al., 2006), adapted for British samples from the original US version (Dupuy, 1984). This is a six-item questionnaire asking participants about their general psychological wellbeing across five domains including; anxiety, vitality, depressed mood, self-control, and positive wellbeing. The measure employs a 5-point Likert scale. An example item is "During the past month how much energy or vitality did you have?" Hunt & McKenna (1992) reported good validity and reliability for the measure across three studies when compared to the longer 22-item General Well-Being Index (Dupuy, 1984), with Cronbach's alphas ranging from 0.80 to 0.92.

5. The Brief COPE (Carver, 1997). This is a 28 item questionnaire asking participants to rate the extent to which they engage in specific coping strategies on a scale from 1 (I haven't done this at all) to 4 (I have done this a lot). The tool comprised 14 subscales, however, Cooper, Katona & Livingston (2008) suggest employing 3 composite scales for which they provided psychometric properties. The three scales include 1) emotional coping such as expressing negative feelings (10 items, total score ranges from 10-40), 2) problem-focussed coping such as thinking of strategies (6 items, total score ranges from 6-24), and 3) dysfunctional coping such as drinking or taking drugs (12 items, total score ranges from 12-48). Cooper, Katona and Livingston (2008) reported good internal consistency across the 3 scales (Cronbach's alpha 0.70 to 0.84), and adequate test retest reliability over 12 months (Pearson's correlation 0.58 to 0.72).

6. Depression Anxiety and Stress Scale 21 (DASS 21; Lovibond & Lovibond, 1995). This is a 21-item questionnaire comprising 3 scales measuring depression, stress, and anxiety. Each item asks participants to rate (on a 4-point Likert scale) the extent to which a statement could be applied to them when they consider how they have felt over the last week. Example items from the DASS 21 include: "I felt I had nothing to look forward to" (depression scale), "I felt scared without any good reason" (anxiety scale), and "I found it difficult to wind down" (stress scale). The authors report that the DASS 21 achieved good internal consistency for the full scale and each sub-scale (Cronbach's alpha 0.76 to 0.92).

7. Diagnosis of Coeliac Disease. Participants were asked about their diagnosis of CD (i.e., whether they were diagnosed through blood test and or intestinal biopsy, their age at diagnosis, and length of time since diagnosis). They were also asked to give details of any

other medical conditions or food intolerances.

8. About Your Gluten-Free Diet (Dietary self-management): In the absence of a standardised measure of dietary self-management, researchers at the University of Birmingham (Petty, Howard and Law) developed a brief 6-item scale (employing a 5-point Likert scale) to measure self-reported dietary management at home and away from home during the past two weeks (2 items) and in general (2 items). A further two items ask, 1) how concerned they are about accidental gluten-ingestion and 2) how harmful they believe this would be. This generated a dietary self-care score of between 4-20, a dietary concern score of between 2-10, and a total GFD score between 6-30.

9. Dietary Knowledge; To measure their knowledge of gluten-free foods, this section included a brief food quiz asking participants to answer yes/no/don't know as to whether 11 listed foods contain gluten. This generated a total knowledge score of between 0-11.

10. The dietician was asked to complete the clinician-rated dietary self-care measure. Clinicians make judgements about dietary self-management based on discussions they have had with patients in clinic together with past and most recent blood test results. For each consenting participant the dietician was asked to give a rating from 0-5, where 0 represents no or very poor dietary self-management, and 5 represents excellent dietary self-care, using a "Recording Sheet for Health Care Professional". This form had space for the clinician to record each participant's name, participant ID number, the date of their blood test, their blood result (when available), and their own rating of the participant's GFD self-care based on clinical judgement.

Data Analysis

Data were analysed using Predictive Analytics Software (PASW) Statistics version 17 (SPSS, Inc., 2008, Chicago, IL, www.spss.com). Screening was conducted to check the data for errors and to ensure there was no violation of the assumptions for the conduct of parametric analysis. Where violations were detected non parametric analyses were conducted in addition to parametric analyses.

Following descriptive statistical analysis, inferential statistical analyses were conducted. The hypothesised relationships between illness representations, self-efficacy, coping, psychological well-being and dietary self-management were evaluated through bivariate correlational analyses. Given the number of correlations conducted, to avoid making type 1 errors, the level of significance was set at $p < 0.01$. Where bivariate analyses confirmed hypothesised relationships, regression analyses were conducted to identify the unique contribution of each predictor variable to the outcome variables (i.e., health related quality of life, general wellbeing, psychological distress, self-efficacy, and dietary self-care (as measured by self-reported and clinician-rated gluten intake in addition to serum levels of CD antibodies)).

Results

Sample Description

In total 200 questionnaires were handed out. One hundred were given in person at a clinic at site 1 and 100 by post to appropriate patients identified by dieticians from both sites. One hundred and eleven participants returned their questionnaires. Fifteen participants' data were excluded from the analyses. Nine of these did not meet the inclusion

criteria as they reported having co-morbid conditions that impacted on their dietary behaviour (six people, diabetes; one, following a low cholesterol diet; one, bowel cancer; one person, anorexia). A further six questionnaires were excluded because more than 25% of the data was missing.

A sample size of 96 participants was achieved. This was lower than the target sample of 150 and mainly due to low numbers (three only) from site 2. Dietician ratings for dietary self-care were available for 62 participants, and blood results for serum CD antibodies were available for 60 participants. Participants (64 women, 32 men) were aged from 20-86 years (mean age 54.83; SD, 14.11). The majority of the sample were members of Coeliac UK (72.9%) and diagnosed after the age of 17 years (94%). Most were married or cohabiting (77%) and white British (95.8%). Many were highly educated (49.9% reported university or vocational qualifications) and of high occupational status (62.5% reported being in professional, managerial, or technical occupations). No significant differences were found between men and women across demographic characteristics, illness representations, or any of the outcome variables (see Appendix F). Detailed demographic information is available in Appendix G.

Internal Reliability

The majority of measures used achieved good (Cronbach's alpha > 0.8) or satisfactory (Cronbach's alpha 0.6-0.79) levels of internal consistency (see Appendix H for details), however, the IPQR illness coherence scale had a poorer level of internal consistency (Cronbach's alpha, 0.18) and was therefore excluded from further analyses.

Descriptive Statistics

The Kolmogorov-Smirnov test confirmed that the data were not normally distributed across all but the consequence scale. The median and interquartile range values as well as the sample means and standard deviations for all measured variables are presented in Table 1. To put these into context, the scoring range for each of the measures is also provided.

As regards beliefs, the sample attributed, on average, 4 physical symptoms to CD. The sample showed strongly held beliefs about the chronicity of CD, relatively high levels of personal and treatment control, and a clear understanding of CD. Weaker beliefs were found relating to the consequences and the emotional impact of CD. Self-efficacy beliefs for a gluten free diet were very strong with the sample mean being 84% of the maximum possible score. The use of coping strategies was endorsed to a moderate level across all three coping styles (emotional-focused, problem-focused and dysfunctional). Psychosocial outcomes were measured by the HRQoL, DASS, and GWI. Participants generally endorsed reasonable health related quality of life, good general wellbeing, and low levels of psychological distress. Fifteen participants (15%), however, scored above 7 on the depression scale of the DASS (the cut off for moderate depression). Participants generally reported very good gluten free dietary self-care behaviour. For the subsample providing further clinical data, dietician ratings and blood levels for CD antibodies both reflected good dietary self-care. See Table 6 for full details.

Bivariate Correlations

Despite the non-normal distribution of data, regression analyses could still be performed providing the error terms (residuals) within each analysis were normally

distributed (Tabachnick & Fidell, 2007). A decision was, therefore, made to conduct both parametric and non-parametric bivariate correlations. Throughout the results section the parametric model is reported, however, where discrepancies between the Pearson's and Spearman's correlations were found, the latter are reported. As previously discussed, correlations coefficients at a significance of $p < 0.01$ were considered meaningful for this study. In addition, correlation coefficients lying below 0.39 were considered weak, those lying between 0.4-0.69 were considered moderate, and those above 0.7 were considered strong (Cohen & Holliday, 1982).

Correlations Between Illness Representations and Self-efficacy

The strongest association among illness representations was found between the two control dimensions (treatment and personal; $r = .63$, $p < 0.01$). Higher representations of CD as cyclical were related to higher emotional representations ($r = .45$, $p < 0.01$). Representations of illness identity were related to consequence ($r = .23$, $p < 0.05$) and chronicity beliefs ($r = .18$, $p = < 0.05$) but only weakly. Finally, self-efficacy was not strongly related to the dimensions illness representations, given that meaningful correlations for this study have been set at 0.40 and above, although a negative relationship found between cyclical timeline beliefs and self-efficacy came close to this criteria ($r = -.39$, $p < 0.001$).

Table 6: Showing Sample Means, Standard Deviations, and Scale Scoring Ranges for all Measured Variables

Concepts	All scales	N	Mean (SD)	Median (IQR)	Scores Range From	To
Beliefs	IPQR Identity	96	4.3 (4.5)	4.0 (4.0)	0	20
	IPQR Timeline (acute/chronic)	92	23.9 (2.9)	25 (1.0)	6	30
	IPQR Timeline (cyclical)	96	8.5 (3.6)	8.0 (6.00)	4	20
	IPQR Consequences	95	19.0 (4.5)	19.0 (6.0)	6	30
	IPQR Personal Control	95	26.3 (3.8)	27.0 (6.0)	6	30
	IPQR Treatment Control	96	19.5 (3.0)	20.0 (3.0)	5	25
	IPQR Illness Coherence	96	18.3 (2.4)	18.0 (3.0)	5	25
	IPQR Emotional Representations	96	12.8 (5.0)	12.0 (7.0)	6	30
	Self-efficacy for GFD	93	284.0 (44.6)	304.0 (61.3)	0	340
Coping	COPE Problem focused	94	10.2 (4.3)	9.0 (7.0)	6	24
	COPE Dysfunctional	94	14.9 (4.5)	12.30 (5.0)	12	48
	COPE Emotion focused	92	17.0 (5.1)	17.0 (7.0)	10	40
Psychosocial outcomes	HRQoL Gastrointestinal	96	35.3 (5.9)	36.0 (7.0)	7	49
	HRQoL emotional	96	31.3 (5.9)	31.0 (9.0)	7	49
	HRQoL Social Restrictions	87	38.9 (5.2)	41.00 (5.4)	7	49
	HRQoL Disease Worries	96	38.4 (8.6)	41.0 (10.4)	7	49
	HRQoL total	87	107.9 (17.3)	112.0 (21.0)	28	196
	General Wellbeing	96	21.5 (4.7)	22.0 (6.0)	6	30
	DASS Depression	96	3.9 (4.7)	2.0 (6.0)	0	21
	DASS Anxiety	96	2.7 (3.4)	1.0 (3.8)	0	21
	DASS Stress	96	5.8 (5.0)	5.0 (7.0)	0	21
	DASS total	96	12.4 (12.0)	8.5 (14.0)	0	63
	Knowledge (Food quiz)	96	6.5 (2.2)	7.0 (3.0)	0	11
Behavioural outcomes	Self-rated GFD	96	18.3 (2.7)	19.0 (2.0)	4	20
	Dietician-rated GFD	62	4.7 (0.6)	5.0 (0.5)	1	5
Clinical outcome	Serum CD Antibodies (Tissue Transglutaminase IgG Ab)	60	6.1 (11.5) U/mL	1.9 (5.1) U/mL	0 U/mL	No maximum

Correlations Between Outcome Variables

All health related quality of life scales and total scores were moderately or strongly related to one another (r ranged from .40 to .92, $p < 0.001$), with the exception of the relationship between the gastrointestinal and social restrictions scales which was weaker (rho = .33, $p < 0.01$). General wellbeing was associated with the total HRQoL scores (r = .72, $p < 0.01$) and all HRQoL scales (r .53 to .79, $p < 0.01$). The psychological distress scales (depression, anxiety, and stress) and total scores of the DASS were negatively associated with the HRQoL total score (r = -.71, $p < 0.01$) and all HRQoL scales (r = -.60 to -.70, $p < 0.01$). Finally the three measures of dietary self-care were related. Dietician rated GF dietary self-care was moderately related to lower blood levels of coeliac antibodies (r = -.44, $p < 0.01$). This relationship was mirrored more weakly for self reported GF dietary self-care and CD antibodies (r = -.34, $p < 0.01$). Spearman's correlation suggested that dietician and self reported dietary self-care were weakly but positively related, while Pearson's correlation suggested this was a stronger relationship (rho = .35, $p < 0.01$; r = .81, $p < 0.01$). Since the data were not normally distributed the Spearman's is given more weight and it is therefore assumed that the relationship between dietician and self reported dietary self-care was positive but weak, rather than strong.

Given the strong correlations across the scales within the HRQoL and DASS measures, and between the total scores for the DASS, HRQoL, and GWI, further analyses employed the total scores to test hypotheses.

Hypotheses Testing

Table 7 presents Pearson's correlations conducted to investigate the predicted relationships. Where discrepancies were found between the parametric and non-parametric correlations, these will be reported below. A correlation table relating to illness representations and all outcome measures is available in Appendix I.

The first hypothesis was that strong personal control beliefs, a greater sense of illness coherence, and lower emotional representations would be associated with better psychosocial and behavioural outcomes (i.e., lower psychological distress and better health related quality of life, wellbeing, self-efficacy and dietary self-care). Pearson's correlations showed personal control beliefs were weakly positively correlated to clinician rated dietary self-care, but this association was not supported by Spearman's rho ($rho = .19$, $p > 0.05$) and was, therefore, not investigated in further analysis. Personal control beliefs were not significantly related to any other outcome. Due to lack of scale reliability the relationship between illness coherence and outcome could not be investigated. Emotional representations were positively related to psychological distress and negatively related to health related quality of life and general wellbeing. No significant relationships were found between emotional representations and any other outcome variable.

The second hypothesis was that strong illness identity, and strongly held beliefs in severe consequences and a chronic or cyclical timeline would be associated with poorer health outcomes (i.e., increased psychological distress and reduced HRQoL, wellbeing, self-efficacy and dietary self-care). There was a weak positive relationship between illness

identity and psychological distress, and a weak negative relationship between illness identity and health related quality of life and general wellbeing. Identity was not significantly related to any other outcome variable. Moderate correlations between consequence beliefs and increased psychological distress and lower health related quality of life and general wellbeing were also found. Again, consequence beliefs were not significantly related to any other outcome. Finally, beliefs in a cyclical timeline were related to increased psychological distress and decreased health related quality of life, general wellbeing and self-efficacy for following a gluten free diet, however, they were not significantly related to any of the dietary behaviour measures. Chronic timeline beliefs were not significantly related to any outcome. As can be seen for Table 7, most of the predicted correlations were modest (below or around 0.4) but significant at the $p < 0.001$ level.

Table 7: Correlations (Pearson) between Illness Representations and Outcome Measures.

	HRQoL	GWI	DASS	DSE	SR-GFD	CR-GFD	CD Antibodies
Identity	-0.32**	-0.28**	0.31**	-0.03	0.03	-0.01	-0.06
Consequences	-0.53**	-0.39**	0.43**	0.07	0.20	0.18	-0.09
Personal Control	0.07	0.03	-0.04	0.05	0.11	0.31**	-0.03
Timeline Cyclical	-0.45**	-0.38**	0.34**	-0.39*	-0.22	-0.25	0.25
Timeline Chronic	-0.12	-0.17	0.16	-0.01	0.04	0.06	0.10
Emotional Representations	-0.54**	-0.38**	0.46**	-0.12	0.18	-0.02	0.13

Note: *p = 0.01, **p <0.001

Regression Analyses

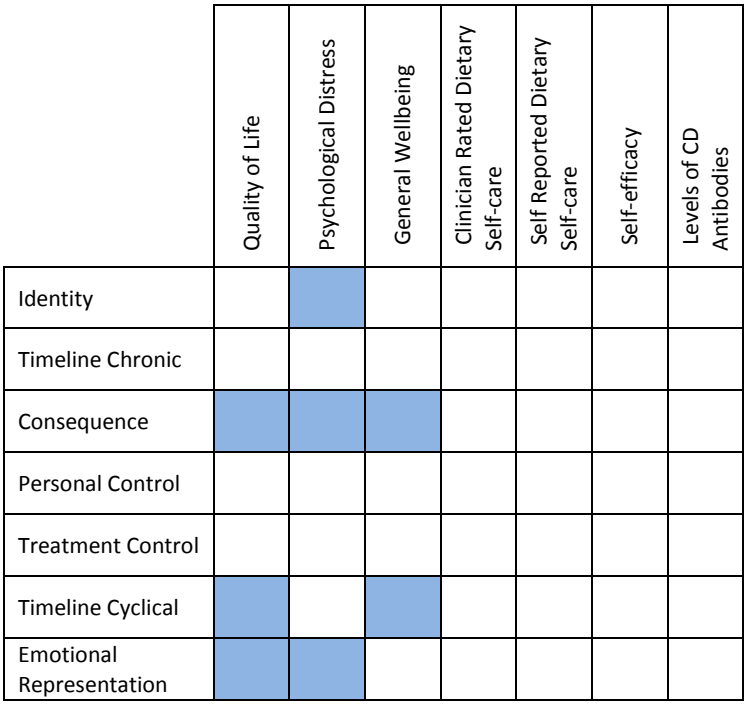
A series of ordinary least squares regression analyses were conducted to assess the strength of association between the various dimensions of illness representation (i.e., identity, timeline chronic, consequence, personal control, treatment control, timeline

cyclical and emotional representation) and each of the outcome variables (i.e., quality of life, psychological distress, general wellbeing, clinician rated dietary adherence, self reported dietary adherence, self-efficacy and levels of CD antibodies).

O'Brien (2007) suggests that a tolerance value of less than 0.1 and or a variance inflation factor (VIF) of greater than 5 indicates significant multicollinearity between the predictor variables. This would mean that estimates of parameter coefficient may be biased. For each of these analyses the tolerance statistic was greater than 0.1 and VIF was not greater than 2.5, and in the majority of cases the VIF was close to 1. Thus it was possible to investigate the relative strength of association for each of the dimensions of illness representations without substantial bias resulting from multicollinearity.

Of the seven remaining dimensions of illness representation consequence (β = -.30, p < 0.05), emotional representation (β = -.27, p < 0.05, and timeline cyclical (β = -.25, p < 0.05) showed a significant negative association with health related quality of life, explaining 49% of the variance (R^2 =.49; F = 10.57; p < 0.01). Similarly, cyclical timeline beliefs (β = -.23, p < 0.05) and consequence (β = -.21. p < 0.05) showed a significant negative association with general wellbeing, explaining 31% of the variance (R^2 =.31; F = 5.37; p < 0.01). Identity (β = .21, p < 0.05), consequence beliefs (β = .22, p < 0.05) and emotional representation (β = .27, P < 0.05) showed a significant positive association with psychological distress, explaining 61% of the variance (R^2 =.61, F = 6.98, p < 0.01). Cyclical timeline (β = -.42, p < 0.05) demonstrated a significant negative association with self-efficacy, however, inspection of a normal P-P plot indicated that the regression residuals were not normally distributed (Tabachnick & Fidell, 2007). No significant associations were found between illness

representations and any of the three behavioural outcome variables. These associations are presented diagrammatically in Figure 1, with shaded areas indicating significant associations, and a table showing the regression analyses is available in Appendix J.



	Quality of Life	Psychological Distress	General Wellbeing	Clinician Rated Dietary Self-care	Self Reported Dietary Self-care	Self-efficacy	Levels of CD Antibodies
Identity		■					
Timeline Chronic							
Consequence	■	■	■				
Personal Control							
Treatment Control							
Timeline Cyclical	■		■				
Emotional Representation	■	■					

Figure 1: Showing Significant Associations (shaded) Between Illness Representations and All Outcome Variables.

Investigating Coping

Pearson's and Spearman's correlations were conducted to explore the relationships between coping (dysfunctional, problem-focussed, and emotion-focussed), illness representations and outcomes (behavioural and psychosocial). A correlation table showing these relationships is available in Appendix K. The three types of coping were moderately inter-related. Dysfunctional coping was related to emotion-focussed ($r = .43$, $p < 0.001$) and problem-focussed ($r = .51$, $p < 0.001$) coping, while emotion-focussed and problem-focussed coping were related to one another ($r = .60$, $p < 0.001$). No significant associations were

found between any type of coping and any measure of behaviour (i.e., self reported, clinician rated) or serology.

Dysfunctional coping was positively related to consequence beliefs ($r = .37$, $p < 0.01$) and emotional representations ($r = .36$, $p < 0.01$). Dysfunctional coping was also negatively related to health related quality of life ($r = -.62$, $p < 0.01$), and wellbeing ($r = -.53$. $p < 0.01$; rho = -.38, $p < 0.01$), and positively related to psychological distress ($r = .67$, $p < 0.01$).

Problem-focussed coping was weakly and positively related to consequence ($r = .30$, $p < 0.01$) and emotional representations ($r = .24$, $p = 0.01$). Problem-focussed coping was also negatively associated with health related quality of life ($r = -.48$, $p < 0.01$) and wellbeing ($r = -.41$, $p < 0.01$), and positively associated with psychological distress ($r = .46$, $p < 0.01$).

Post Hoc Analyses

Self-efficacy

The relationship between self-efficacy and behaviour was investigated. Spearman's correlations indicated that self-efficacy was positively related to self-reported gluten free eating (rho = .77, $p < 0.01$), and dietician ratings (n=62; rho = .36, $p < 0.01$). Self-efficacy was also negatively related to blood levels of CD antibodies (n=59; rho = -.33, $p < 0.01$).

Discussion

The recruited sample generally showed well-adjusted illness representations (i.e., strong control beliefs and weaker beliefs around consequence and emotional impact). The sample endorsed moderate illness identity (symptomology) and strongly held beliefs in a chronic timeline for CD. In addition, participants generally reported high self-efficacy for

following a gluten free diet and this was reflected in high levels of dietary self-care. This was supported by self and dietician ratings and objective serology. Psychosocial outcomes were also good. In contrast to previous findings (Häuser et al., 2006; Östlund et al., 2009) participants reported reasonable health related quality of life and wellbeing. In contrast to findings by Lee and Newman (2003), there were no differences between men and women in quality of life or any other outcome variable. This may reflect that participants in this study were not newly diagnosed and had been following a GFD for at least one year, as in Casellas et al. (2008) who reported reasonable quality of life for a similar sample. While most participants reported low psychological distress, fifteen reported moderate depression. This number is, however, lower than those found by Ciacci et al. (2007), where one third of their CD sample reported levels of depression.

This research study tested two hypotheses regarding the relationships between illness representations and outcomes among a sample of people with CD. Firstly, that higher scores for reported control (personal and treatment), illness coherence beliefs, and lower reported emotional representations would be related to better outcomes for psychological distress, health related quality of life, wellbeing, self-efficacy for gluten free eating and dietary self-care. Following bivariate correlations multivariate regression analyses were undertaken, only regression analyses will be discussed.

In relation this hypothesis, regression showed that low scores for emotional representations were related to better reported health related quality of life and lower reported psychological distress. This finding is in line with those of Ford et al., (in press). No relationship was found, however, between emotional representations and dietary self-care.

Also, and in contrast to Ford et al., the hypothesised relationship between control beliefs and self-efficacy, dietary behaviour, or any other outcome variable was not found. Additionally, weak correlations between cyclical timeline beliefs and self-efficacy, health related quality of life and psychological distress were not supported in regression analyses.

The second hypothesis was that higher scores for illness identity, consequence beliefs, and beliefs in a chronic or cyclical timeline for CD would be related to poorer outcomes for the same variables. In line with this, regression analyses demonstrated that stronger beliefs in severe consequences for CD were related to lower reported quality of life and wellbeing, and higher psychological distress. This finding is in keeping with meta-analyses findings for 22 other health conditions (Hagger and Orbell, 2003). Similarly, stronger beliefs in a cyclical timeline were related to reduced quality of life and wellbeing. Higher illness identity scores were associated with psychological distress. In contrast to the hypothesis, consequence, timeline (chronic and cyclical), and illness identity beliefs were not related to dietary self-care.

In summary, the regression models indicated that illness representations explained 60%, 49%, and 31% of the variance in psychological distress, health related quality of life, and general wellbeing respectively.

As regards coping, Hagger and Orbell (2003) previously found that, across 43 studies, beliefs about personal control and illness identity were related to coping such that a greater sense of personal control was related to more active (helpful) coping while higher illness identity scores were rated to avoidance (unhelpful) coping. Within the current CD sample, correlational analyses showed that the three types of coping (dysfunctional, problem-

focussed, and emotion-focussed) were related to one another. While emotional focused coping was not strongly related to any outcome, dysfunctional coping and problem focussed coping were both related to psychosocial outcomes in a similar way. Dysfunctional coping (thought to be an unhelpful coping style) was related to stronger beliefs about severe consequences and the emotional impact (representation) of CD. In addition dysfunctional coping was also related to lower quality of life and wellbeing, and increased psychological distress. Problem focussed coping (thought to be a helpful coping style) was also related to stronger beliefs about severe consequences and the emotional impact of CD, and the same negative psychosocial outcomes (i.e., lower health related quality of life and wellbeing, and higher psychological distress). This finding contrasts with Hagger and Orbell and is difficult to interpret. It may be that reduced quality of life and increased distress bring about efforts to cope in both healthy and unhealthy ways, but none of this appears to relate to outcome measures of dietary self-care. It may also be that these two dimensions of illness representations impact on coping differently with, for example, consequence beliefs promoting problem-focussed coping and higher emotional representations underpinning dysfunctional coping. Further research would be needed, with normally distributed samples, to investigate the role of coping in CD.

Self-efficacy was the only measured construct to be related to dietary behaviour. Higher self-efficacy scores were strongly related to higher self reported GFD scores, and more weakly related to higher clinician rated GFD scores and lower CD antibodies. Regression analysis, due to lack of normally in error terms, was unable to determine whether a weak relationship between high cyclical timeline beliefs and lower self-efficacy for a GFD reflected a meaningful association.

Clinical Implications

These findings suggest that how an individual understands CD is associated with how they experience it. In particular there is an opportunity for health care professionals to support people with CD to have realistic beliefs about the consequences of CD, because a belief in very serious consequences can lead to reduce quality of life, wellbeing and psychological functioning. Similarly, assessment and intervention aimed at avoiding or reducing the emotional impact of CD would also support psychosocial health. Assessing and promoting self-efficacy for a GFD may offer the best opportunity to support good dietary self-care among this population.

Limitations

This was a selected sample of highly educated and occupationally successful people who were coping well with CD, and accessing regular support from their dietician and the charity Coeliac UK (where most had current membership). The sample also reported few gastrointestinal symptoms and high levels of health-related quality of life and psychological wellbeing. This may reflect that those with lower motivation for self-care or with more casual illness representations may have been more likely to skip follow-up appointments, making it unlikely that they would be recruited. Thus it cannot be claimed that the sample was fully representative of the CD population, and this limits possible conclusions. In addition, since previous research has suggested regular dietician support, high quality of life and reduced depression is associated with better dietary self-care (Addolorato et al., 1996), the current sample may be biased toward dietary self-care and not reflect the levels of difficulty in managing CD that might bring about some of the relationships previously found

between illness representation, coping, and outcome.

Most data were not normally distributed which limited analysis options. Additionally, the coherence scale did not achieve sufficient internal consistency to contribute to findings so the hypothesis that illness coherence would be related to psychosocial health and dietary self-care could not be tested.

This was a cross-sectional study offering a snap shot of the relationships between the variables of interest at one time period. As such, it was not able to offer information about how these variables relate over time, for example, how reported illness representations might have impacted on future quality of life or behaviour.

Finally, poor recruitment figures at site two meant the desired sample size was not achieved, and this could be expected to reduce the power to detect meaningful effects.

Further Research

This research has supported the utility of the concept of illness representations in understanding psychosocial, but not behavioural, outcomes among adults with coeliac disease. Previous findings in relation to illness identity and control belief were not supported here. Further research with larger, heterogeneous, samples would be required to illuminate exactly how, and under what circumstances, each aspect of illness representation influences the experience and self-management of CD. Findings for this sample have also suggested a role for coping in psychosocial outcomes and a clear role for self-efficacy in behavioural outcomes. Further research should aim to clarify the nature of these roles in terms of whether they cause or mediate an effect on these outcomes.

This study employed three measures of dietary self-care; (a) self reported, (b)

dietician rated, and (c) blood results. To the author's knowledge this was the first study to employ an objective clinical measure of recent gluten ingestion. Levels of CD antibodies were strongly related to dietician ratings; not surprising given the dietician employed serology to assess how well participants were following a GFD. Blood results were less strongly related to self reported self-care. This may be because participants had less information to go on when rating their GFD. The use of CD serology as a measure of recent gluten ingestion could enhance future research, particularly in longitudinal designs which can capture whether antibody levels are reducing or increasing from a previous level. There would be a need to employ standardised time periods between blood tests. To be of most use, CD blood tests should be taken within the same timeframe as the self report measures of gluten free dietary self-care.

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Public Domain Briefing Paper

Investigating the Influence of Illness Representations on Health and Dietary Outcomes for Coeliac Disease.

Coeliac disease (CD) is a common chronic autoimmune disorder of the small intestine. It features a permanent sensitivity to certain amino acids found in wheat, barley, and rye. Left untreated individuals experience a range of symptoms due to abdominal inflammation and malabsorption of iron, calcium and fibre. These individuals are also at risk of developing a number of other health conditions such as type 1 diabetes, infertility problems, and gastrointestinal cancer.

People with CD can very effectively manage their condition by sticking to a life-long gluten free diet. This, however, can feel very restrictive and impinge on their quality of life. Until recently, most research into coeliac disease focussed on biological causes and treatments. Recent research is concerned with the psychological and social impact of the condition. This research suggests that people who have CD are more likely to become anxious and depressed compared to people without CD.

It may also be true that the way people understand their CD will influence the way in which they try to management it. In turn, this may impact on their health related quality of life, mood, and sense of wellbeing. Health Psychologists have suggested that Illness Representations (beliefs) might explain how this understanding might influence coping and behaviour. In its current form this model suggests that all people understand any health condition in terms of the same key elements (called illness representations). For example, an individual with CD might ask themselves (a) what is my condition called and what symptoms do I have, b) what caused it, (c) are the consequences serious, (d) does it make any coherent

sense to me, (e) can I do anything to cure or control it , (f) how safe and effective might any treatments be, g) will it last a short time, a long time, or will it come and go in cycles, and (h) how is it affecting me emotionally. The model also suggests that people use this understanding (i.e., their answers to these questions) to make an action plan. Following a period of action, individuals then evaluate how they are doing and whether their action plan is working. Using this feedback, individuals then refine their understanding and action plans accordingly.

The concept of Illness Representations has been employed successfully to understand how people manage a number of health conditions. This study was among the first to apply the idea to people living with coeliac disease. Between September 2009 and March 2010, we recruited adults with CD attending dietician clinics at two sites in the UK. People choosing to take part were asked to complete a number of questionnaires. These were designed to measure their illness understandings (representations), their confidence in sticking to a gluten free diet (self-efficacy), their coping strategies, and their behaviour (i.e., how well they thought they were doing with their diet). They also completed questionnaires about their current mood, health related quality of life, and their general sense of wellbeing. In addition to this, participants gave permission for, (a) us to access their most recent blood test for coeliac antibodies (these would be raised if a person with CD was eating gluten in their diet), and (b) us to ask their dietician to rate how well the participant was sticking to their gluten free diet.

Through statistical analyses of all the information we gathered our findings suggested that most of our participants were doing well with their diet (in terms of their own sense of

how they were doing, their dietician's rating, and their blood test results). Most felt they had a good health quality of life and wellbeing, and low levels of psychological distress. Most, also, felt very confident about sticking to a gluten free diet. This finding is in line with previous research that has shown that people who attend regular dietician clinics tend to find it easier to stick to a gluten free diet.

We conducted some further analyses to look at the relationships between the various elements of illness understanding (representations) and how people were managing and experiencing their CD.

We found that where people believed their CD would have serious consequences and symptoms that would come and go in cycles, people reported lower health quality of life and wellbeing, and higher psychological distress. These beliefs did not, however, relate to how well people managed their gluten free diet. We expected to find that where people believed they had more control over their condition, people would report lower psychological distress, better health quality of life and general wellbeing. In contrast to our expectations, our findings did not show any relationship between control beliefs and any aspect of experiencing or managing CD.

We found that the way people cope with their CD was related to some of their illness beliefs and their quality of life, psychological health and wellbeing. Beliefs about the consequences and emotional impact of CD were related to coping such that people who reported that their CD had fewer severe consequences and less of an emotional impact on them also reported reduced use of either problem-focussed (helpful) or dysfunctional (unhelpful) coping strategies. In contrast, beliefs about more severe consequences and

emotional impact were related to increased use of both helpful and unhelpful coping. Interestingly, increased reporting of either type of coping was related to reports of lower health-related quality of life and wellbeing, and higher psychological distress. Despite our findings in relation to coping, beliefs and psychological wellbeing, we did not find any relationship between reported coping and dietary behaviour. These findings are difficult to explain. Dysfunctional coping is considered unhelpful while problem-focussed coping is considered more helpful. Emotion-focussed coping, depending on its nature and context, can be considered either helpful or unhelpful. It may be that reduced quality of life and increased distress bring about efforts to cope in both healthy and unhealthy ways. Our findings suggest that the extent to which people follow a gluten free diet is most related to their confidence in doing so (their self-efficacy). More research would be needed to understand this better.

Further Research

Our findings suggest that illness representations may usefully explain some but not all of the relationships between how people understand and manage living with CD. Further research is needed to confirm and refine our understanding of these relationships. Blood results, and dietician ratings of dietary self-care are recommended as valuable ways of assessing behaviour in future research.

Clinical Implications

These findings suggest that how an individual understands CD is associated with how they experience it. In particular there is an opportunity for health care professionals to support people with CD to have realistic beliefs about the consequences of CD, because a

belief in very serious consequences can lead to reduced quality of life, wellbeing and psychological functioning. Similarly, assessment and intervention aimed at avoiding or reducing the emotional impact of CD would also support psychosocial health. Assessing and promoting self-efficacy for a GFD may offer the best opportunity to support good dietary self-care among this population. This supports the recent trend within UK health care services to provide regular support for people with CD, through specialist dietician led clinics.

Appendices

Appendix B. The Theory Coding System & a Table of common theories and theoretical constructs (provided by Michie & Prestwich, 2010).

Theory Coding Scheme 12e: Instructions

The coding scheme that follows comprises 19 items. For each item, code as Yes or No. When 'Yes', state the supporting evidence and its location, as follows: ([insert page number], [insert paragraph number]).

The coding scheme is based on the *explicit* use of theory. Consequently, even when theory-relevant information is implied but is not stated explicitly, the related items should be coded as 'no'.

Defining Terms

Please refer to the definitions (see below) during coding:

Theory (or Model)

'a set of interrelated concepts, definitions and propositions that present a *systematic* view of events or situations by specifying relations among variables, in order to *explain* or *predict* the events or situations' (Glanz & Rimer, 1995). Examples include: TPB, TRA, HBM, stage of change/trans-theoretical model etc.)

Theory-relevant construct

A construct (a key concept, excluding behaviour) within a theory/model upon which the intervention is based.
Please refer to the '*Table of Theories*' to identify whether a particular construct belongs to the specified theory.

Predictors

Constructs that are not explicitly linked to a theory by the authors, but are targeted for intervention (as a means to change behaviour) because they predict behaviour. Predictors must only be coded if the author has presented evidence that the construct predicts/correlates with/causes behaviour. Predictors do not include actual behaviour, self-reported or otherwise (e.g. amount of time spent exercising), or biological factors (e.g., age, sex).

Intervention Technique
Strategy used to change behaviour, theory-relevant construct or predictor (e.g., providing information on consequences; prompting specific goal setting; prompting barrier identification; modelling the behaviour; planning social support).

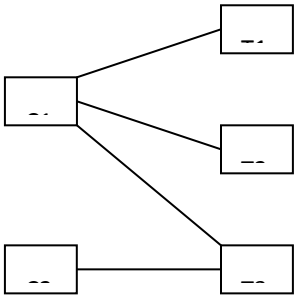
Item Specific Information
i. Items 4-13 and 15-16: Code theory-relevant constructs and predictors separately.

ii. Items 17-19: Only code according to the theory base of the intervention (i.e. not predictors)

iii. Items 7-9: In some cases, items 7, 8 and 9 may all be coded as 'no' (e.g., where techniques are listed but theory-relevant constructs/predictors are not, or vice-versa).
If item 7 is coded 'yes' then items 8 and 9 must be coded 'no'.
It is possible for items 8 and 9 to both be coded as 'yes'.
In instances where the name of the *construct* might overlap with the name of the technique (e.g., tips on *social support* were given; exercise *benefits* were discussed), code this as a direct link between technique and construct (i.e. they do not need to be written in the form 'tips on social support [technique] were used to target social support [construct]'; exercise benefits were discussed [technique] to target perceived benefits [construct]).

iv. Footnotes:
[1] *Item 7:* All intervention techniques (T) are linked to at least one theory-relevant construct/predictor (C). Examples of meeting this criterion:
- T1 & T2 are used to change C1; T3 is used to change C1 and C2. Techniques 1-3 are the only intervention techniques used (see DIAGRAM 1).
- T1 used to change C1; T2 used to change C2; T3 used to change C3

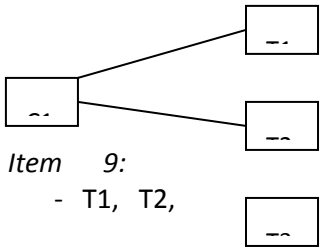
DIAGRAM 1: Example: All intervention techniques (T) are linked to at least one theory-relevant construct/predictor (C)



[2] *Item 8:* At least one, but not all, of the intervention techniques (T) are linked to at least one theory-relevant construct/predictor (C). At least one technique, therefore, is not linked to any theory-relevant construct/predictor. Examples of meeting this criterion:

- T1 and T2 are used to change C1; T3 is used but not linked to a construct/predictor (see DIAGRAM 2).
- T1 used to change C1; T2 used to change C1 and C2; T3 is used but not linked to a construct/predictor.

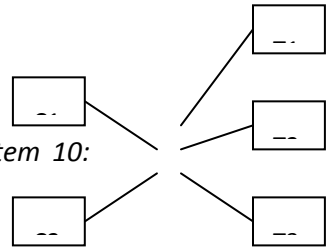
DIAGRAM 2: Example: At least one, but not all, of the intervention techniques (T) are linked to at least one theory-relevant construct/predictor (C)



[3] *Item 9:* Group of techniques (T) are linked to a group of theory-relevant constructs/predictors (C). Example of meeting this criterion:

- T1, T2, T3 are used to change C1, C2 (see DIAGRAM 3).

DIAGRAM 3: Example: Group of techniques (T) are linked to a group of theory-relevant constructs/predictors (C)



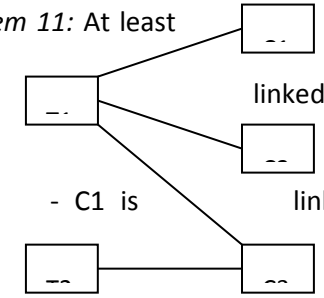
[4] *Item 10:* All constructs within a stated theory/all stated predictors (C) are linked to at least one intervention technique (T). Examples of meeting this criterion:

- C1 & C2 are linked to T1; C3 is linked to T2. Constructs 1-3 are the only constructs within the theory specified in item 5 (see DIAGRAM 4).
- C1 is linked to T1; C2 is linked to T2; C3 is linked to T3

To determine which theoretical constructs should be identified and then linked to at least one intervention technique, please consult the '*Table of Theories*'.

DIAGRAM 4: Example: All constructs within a stated theory/all predictors (C) are linked to at least one intervention technique (T)

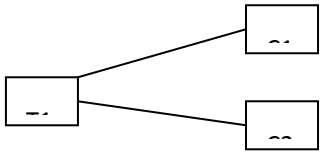
[5] *Item 11:* At least one, but not all, of the constructs within a stated theory/all stated predictors (C) are linked to at least one intervention technique (T). At least one construct within a stated theory, therefore, is not linked to any intervention technique. Examples of meeting this criterion:



- C1 and C2 are linked to T1; C3 is not linked to an intervention technique- or is not highlighted by the authors (see DIAGRAM 5).
- C1 is linked to T1; C2 is linked to T1 and T2; C3 is not linked to an intervention technique- or is not highlighted by the authors.

To determine which theoretical constructs should be identified and then linked to at least one intervention technique, please consult the '*Table of Theories*'.

DIAGRAM 5: Example: At least one, but not all, of the constructs within a stated theory/stated predictors (C) are linked to at least one intervention technique (T)



[6] *Item 13*
Reliability/Validity.

- To judge measures as valid authors should present reference to relevant analyses the authors have conducted *or* with reference to such analyses conducted by others (including via citation).
- To judge a measure as reliable, the authors should test whether their measure, for their sample, is reliable by conducting and reporting relevant analyses.
- For the purposes of developing the scheme, we have used the following criteria (alpha >.7; test-retest reliability >.7; reference to satisfactory validity).
- Single item measures are seen as reliable/valid only with appropriate supporting evidence (e.g., test-retest reliability >.7). However, given

the various issues connected with single item measures, those using the scheme may wish to highlight studies that have incorporated single-item, but otherwise reliable/valid, measures (e.g., using *) to differentiate these from studies employing reliable/valid multi-item scales.

- Where authors have used multiple measures (or sub-scales) and these have subsequently been combined into a single index (e.g., for the purpose of analysis), the authors should cite evidence for the reliability/validity of the overall index and/or for each of the component measures.

- Where authors have used multiple measures and these have not been combined into a single index (e.g., for the purpose of analysis) then the authors should cite evidence for the reliability/validity of at least one of the measures.

- Those using the Theory Coding Scheme for review purposes may wish to alternatively define the parameters required to demonstrate satisfactory reliability and validity,

[7] Items 13a), 13b), 13c), 13d)
Where appropriate evidence for at least one type of reliability/validity is reported, items 13a) (reliability) and 13c) (validity) should be coded 'yes' and items 13b) (reliability) and 13d) (validity) should be coded 'no'.

[8] *Item 14*
Randomization.

- In instances where authors report randomization checks that demonstrate equality across experimental conditions (or inequalities between experimental conditions are statistically controlled) but they have excluded at least one of the measures that could have been included in randomization checks, this should still be coded as an instance of successful randomization.

- Where groups are allocated to condition, the authors should note how the groups were randomized to condition (e.g., coin toss).

- Method of randomization refers specifically to the method used to generate the random allocation sequence (e.g., using a random number generator) rather than types of randomization (e.g., stratified random sampling).

Additional Notes:

1. When more than one intervention is used (excluding the control group), the items should be coded separately for each intervention
2. Note for Stage of Change/Trans-Theoretical Model: While the construct 'stage of change' may either be used to select recipients of an intervention (item 4) or to tailor an intervention (item 6), 'stage of change' measures should not be coded for items 7-16. However, self-efficacy and decisional balance, both constructs within the TTM, should be coded throughout.

Item No.	Item	Description	Yes/ No/ Don't know	List with location	
1	*Theory/model of behaviour mentioned*	Models/theories that specify relations among variables, in order to *explain* or *predict* behaviour (e.g., TPB, SCT, HBM) are mentioned, even if the intervention is not based on this theory			
2	*Targeted construct mentioned as predictor of behaviour*	('Targeted' construct refers to a psychological construct that the study intervention is hypothesised to change). Evidence that the psychological construct relates to (correlates/predicts/causes) behaviour should be presented within the introduction or method (rather than the Discussion).		**Location of evidence that construct relates to behaviour:** **Location that this predictor is targeted by the intervention:**	
3	*Intervention based on single theory*	The intervention is based on a single theory (rather than a combination of theories or theory + predictors)			
4	*Theory/ predictors used to select recipients for the intervention*	Participants were screened/selected based on achieving a particular score/level on a theory-relevant construct/predictor		**Construct (Theory)**	**Predictor**
5	*Theory/ predictors used to select/develop intervention techniques*	The intervention is explicitly based on a theory or predictor or combination of theories or predictors		**Theory**	**Predictor**
6	*Theory/ predictors used to tailor intervention techniques to recipients*	The intervention differs for different sub-groups that vary on a psychological construct (e.g., stage of change) or predictor at <u>baseline</u>		**Construct**	**Predictor**
7	*<u>All</u> intervention techniques are explicitly linked to at least one theory-relevant construct/*	Each intervention technique is explicitly linked to at least one theory-relevant construct/predictor.[1]		**Construct (list links)**	**Predictor (list links)**

	predictor				
8	*<u>At least one</u>, but not all, of the intervention techniques are explicitly linked to at least one theory-relevant construct/ predictor*	At least one, but not all, of the intervention techniques are explicitly linked to at least one theory-relevant construct/ predictor.[2]		**Construct (list links)**	**Predictor (list links)**
9	*Group of techniques are linked to a group of constructs/ predictors*	A cluster of techniques is linked to a cluster of constructs/ predictors.[3]		**List clusters of techniques/constructs**	**List clusters of techniques/predictors**
10	*<u>All theory-relevant constructs/predictors</u> are explicitly linked to at least one intervention technique*	Every theoretical construct within a stated theory, or every stated predictor (see item 5), is linked to at least one intervention technique.[4]		**Construct (list links)**	**Predictor (list links)**
11	*<u>At least one</u>, but not all, of the theory relevant constructs/predictors are explicitly linked to at least one intervention technique*	At least one, but not all, of the theoretical constructs within a stated theory or at least one, but not all, of the stated predictors (see item 5) are linked to at least one intervention technique.[5]		**Construct (list links)**	**Predictor (list links)**

12	*Theory-relevant constructs/ predictors are measured*	a) At least one construct of theory (or predictor) mentioned in relation to the intervention is measured POST-INTERVENTION. b) At least one construct of theory (or predictor) mentioned in relation to the intervention is measured PRE AND POST-INTERVENTION.		**Construct**	**Predictor**
13	*Quality of Measures*[6]	a) All of the measures of theory relevant constructs/predictors had some evidence for their reliability[7] b) At least one, but not all, of the measures of theory relevant constructs/predictors had some evidence for their reliability c) All of the measures of theory relevant constructs/predictors have been previously validated d) At least one, but not all, of the measures of theory relevant constructs/predictors have been previously validated e) The behaviour measure had some evidence for its reliability f) The behaviour measure has been previously validated		**Construct**	**Predictor**
14	*Randomization of participants to condition*[8]	a) Do the authors claim randomization? b) Is a method of random allocation to condition described (e.g., random number generator; coin toss) c) Was the success of randomization tested? d) Was the randomization successful (or baseline differences between intervention and control group statistically controlled)?			

15	*Changes in measured theory-relevant constructs/ predictor*	The intervention leads to sig. change in at least one theory-relevant construct/predictor (vs. control group) in favour of the intervention.		**Construct**	**Predictor**
16	*Mediational analysis of construct/s / predictors*	In addition to 15, do the following effects emerge?: a) Mediator predicts DV? (or change in mediator leads to change in DV) b) Mediator predicts DV (when controlling for IV)? c) Intervention does not predict DV (when controlling for mediator)? d) Mediated effect statistically significant?		**Construct**	**Predictor**
17	*Results discussed in relation to theory*	Results are discussed in terms of the theoretical basis of the intervention			
18	*Appropriate support for theory*	Support for the theory is based on appropriate mediation OR refutation of the theory is based on obtaining appropriate null effects (i.e. changing behaviour without changing the theory-relevant constructs).			
19	*Results used to refine theory*	The authors attempt to refine the theory upon which the intervention was based by either: a) adding or removing constructs to the theory, or b) specifying that the interrelationships between the theoretical constructs should be changed and spelling out which relationships should be changed		**a) Constructs added or removed from theory:** **b) Interrelationships between the theoretical constructs to be changed:**	

Table of Theories

Theory	***Theory-relevant constructs***
Theory of Reasoned Action	1. **Attitudes**; 2. **SN**; 3. **Intentions**
Theory of Planned Behaviour	1. **Attitudes**; 2. **SN**; 3. **PBC**; 4. **Intentions**
Trans-Theoretical Model/Stages of Change	1. **Self-Efficacy** (person's confidence in performing a particular behaviour); 2. **Decisional Balance**
SCT	1. **Self-Efficacy** (person's confidence in performing a particular behavior)/ **Behavioral capability** (Knowledge and skill to perform a given behavior); 2. **Action-Outcome Expectancies** (extent that one's actions are seen as instrumental for the outcome/values associated with outcomes)/**attitudes**; 3. **Barriers** (including changes to environment/emotional barriers or one's perceptions of them). The following constructs are also related to the theory (and subsequently should be listed when they are cited by the authors): *Behavioral capability:* Knowledge and skill to perform a given behavior; *Attitudes (outcome-expectancies):-* *Expectations:* Anticipatory outcomes of a behavior; *Expectancies:* The values that the person places on a given outcome, incentives; *Self-control:* Personal regulation of goal-directed behavior or performance *Goals?*

Health Belief Model	1. **Perceived Susceptibility**; 2. **Perceived Severity**; 3. **Perceived Benefits** (one's belief in the efficacy of the advised action to reduce risk or seriousness of impact); 4. **Perceived Barriers**; 5. **Cues to Action**; 6. **Self-Efficacy** (added by Rosenstock et al., 1988)
Protection Motivation Theory (PMT)	1. **Intention**; 2. **PBC**; 3. **Perceived Severity**; 4. **Perceived Vulnerability**; 5. **Response Efficacy**; 6. **Response Costs**; 7. **Fear** (now added to the model),
Rubicon Model / Model of Action Phases (Heckhausen, 1991; Gollwitzer, 1990)	1. **Motivation** (e.g., intention); 2. **Volition** (e.g., planning)

Appendix E. Table of Items by Measure Completed by Participants.

Measure and Sub-scale	Number of items	Item No	Item description
IPQ-R (REVERSE = recode these items)			
Identity	20	1	Abdominal pain
		2	Sore throat
		3	Nausea
		4	Weight loss
		5	Fatigue
		6	Stiff joints
		7	Sore eyes
		8	Headaches
		9	Upset stomach/ diarrhoea
		10	Sleep difficulties
		11	Dizziness
		12	Loss of strength
		13	Bloating
		14	Excessive wind
		15	Breathlessness
		16	Constipation
		17	Heartburn/ indigestion
		18	Mouth ulcers
		19	Wheeziness
		20	Hair loss
Timeline (acute/chronic)	6	1	My CD will last a short time. REVERSE
		2	My CD is likely to be permanent rather than temporary.
		3	My CD will last for a long time.
		4	My CD will pass quickly. REVERSE
		5	I expect to have CD for the rest of my life.
		18	My CD will improve in time. REVERSE
Consequences	6	6	My CD is a serious condition.
		7	My CD has major consequences on my life.
		8	My CD does not have much effect on my life. REVERSE
		9	My CD strongly affects the way others see me.
		10	My CD has serious financial consequences.
		11	My CD causes difficulties for those who are close to me.
Personal control	6	12	There is a lot which I can do to control my symptoms.
		13	What I do can determine whether my CD gets better or worse.
		14	The course of my CD depends on me.
		15	Nothing I do will affect my CD. REVERSE
		16	I have the power to influence my CD.
		17	My actions will have no effect on the outcome of my CD. REVERSE
Treatment control	5	19	There is very little that can be done to improve my CD. REVERSE
		20	My gluten-free diet will be effective in curing my CD.
		21	The negative effects of my CD can be prevented (avoided) by my diet.
		22	My gluten-free diet can control my CD.
		23	There is nothing that can help my CD. REVERSE
Illness coherence	5	24	The symptoms of CD are puzzling to me. REVERSE
		25	My CD is a mystery to me. REVERSE
		26	I don't understand my CD. REVERSE
		27	My CD doesn't make any sense to me. REVERSE
		28	I have a clear picture or understanding of my CD.
Timeline (cyclical)	4	29	The symptoms of my CD change a great deal from day to day.
		30	My symptoms come and go in cycles.
		31	My CD is very unpredictable.
		32	I go through cycles in which my CD gets better and worse.
Emotional	6	33	I get depressed when I think about my CD.

Measure and Sub-scale	Number of items	Item No	Item description
representations		34	When I think about my CD I get upset.
		35	My CD makes me feel angry.
		36	My CD does not worry me. REVERSE
		37	Having CD makes me feel anxious.
		38	My CD makes me feel afraid.
General Wellbeing index (NO REVERAL NEEDED AS BUILT INTO REPONSE MODE)			
Total No Items	6	1	Have you been bothered by your nerves during the past month?
		2	During the past month how much energy or vitality did you have?
		3	Have you felt disheartened and sad over the past month?
		4	During the past month have you felt emotionally stable and sure of yourself?
		5	During the past month how cheerful have you been?
		6	Have you felt tired, worn out or exhausted during the past month?
Celiac Disease Questionnaire (NO REVERAL NEEDED AS BUILT INTO REPONSE MODE)			
Gastrointestinal symptoms	7	1	Sudden urge for bowel movement
		5	Loose bowels
		7	Abdominal cramps
		11	Bloating
		13	Incomplete bowel evacuation
		17	Belching
		20	Nausea
Emotional well-being	7	2	Physically fatigued
		3	Restless
		8	Intellectually fatigued
		10	Depressed
		14	Relaxed
		16	Tearful
		19	Happy
Social restrictions	7	4	Invitation/dinner
		9	Recreation/sports
		21	Lack of understanding family/friends
		15	Excluded from others
		18	Sexual activities
		22	Lack of understanding colleagues
		23	Professional career
Disease related worries	7	6	Inheritance to children
		12	Afraid of getting cancer
		24	Expenses/time gluten-free food
		25	Problems with health insurance provider
		26	Lack of expertise from
		27	Diagnosed too late
		28	Fear of medical examinations doctors
Total No items	28		
Depression Anxiety and Stress Scale (NO REVERSAL)			
Depression	7	3	I couldn't seem to experience any positive feeling at all
		5	I found it difficult to work up the initiative to do things
		10	I felt that I had nothing to look forward to
		13	I felt down-hearted and blue
		16	I was unable to become enthusiastic about anything
		17	I felt I wasn't worth much as a person
		21	I felt that life was meaningless
Anxiety	7	2	I was aware of dryness in my mouth
		4	I experienced breathing difficulty (e.g., excessively rapid breathing, breathlessness in the absence of physical exertion)

Measure and Sub-scale	Number of items	Item No	Item description
		7	I experienced trembling (e.g., in the hands)
		9	I was worried about situations in which I might panic and make a fool of myself
		15	I felt I was close to panic
		19	I was aware of the action of my heart in the absence of physical exertion (e.g., sense of heart rate increase, heart missing a beat)
		20	I felt scared without any good reason
Stress	7	1	I found it hard to wind down
		6	I tended to over-react to situations
		8	I felt that I was using a lot of nervous energy
		11	I found myself getting agitated
		12	I found it difficult to relax
		14	I was intolerant of anything that kept me from getting on with what I was doing
		18	I felt that I was rather touchy
Total items	21		
Self-Efficacy (NO REVERSAL)			
CD-SES	34	1	When I'm watching television at home
		2	When I'm feeling tired or bored
		3	When I'm alone at home
		4	When I'm feeling anxious, stressed or worried
		5	When I see friends eating non gluten-free foods
		6	When I am upset
		7	When eating out at my favourite restaurant
		8	When I'm on holiday and staying in a hotel
		9	When I'm feeling annoyed or angry
		10	When it is difficult to get hold of the foods I should eat for my gluten-free diet because the chemist cannot fill my prescription
		11	When I'm out and about and get very hungry
		12	When I'm feeling sad
		13	When I'm celebrating with others (e.g. at a birthday party)
		14	When I'm preparing non gluten-free food for other people
		15	When eating out at a friend's house
		16	When I'm offered non gluten-free foods
		17	When non gluten-free foods are available at home
		18	When it is difficult to get hold of the foods I should eat for my gluten free diet because the supermarket does not have my usual items
		19	When I'm eating out at an unknown restaurant
		20	When I am ill
		21	When I'm on holiday and catering for myself (e.g. self catering)
		22	At parties when non gluten-free food is offered to me
		23	When I am in a hurry
		24	When I'm preparing my own meal
		25	When I'm faced with appealing foods that are not gluten-free in a supermarket, vending machine, or café
		26	When my life doesn't go to plan
		27	When I'm feeling well (i.e. healthy, no symptoms)
		28	When I'm on holiday and eating in restaurants
		29	When I want more variety in my diet
		30	When I'm craving foods containing gluten
		31	When I'm on the way to or from work
		32	When I'm staying in hospital
		33	When I'm travelling (e.g. by aeroplane, train etc.)
		34	When I'm not sure if something is gluten-free or not
Brief COPE (NO REVERSAL)			

Measure and Sub-scale	Number of items	Item No	Item description
Total items	28		
Problem-focused	6	Active cop 2	2. I've been concentrating my efforts on doing something about the situation I'm in.
		7	7. I've been taking action to try to make the situation better.
		Use of ins 10	10. I've been getting help and advice from other people.
		23	23. I've been trying to get advice or help from other people about what to do.
		Planning 14 25	14. I've been trying to come up with a strategy about what to do.
			25. I've been thinking hard about what steps to take.
Dysfunctional	12	Self-distra 1	1. I've been turning to work or other activities to take my mind off things.
		19	19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.
		Denial 3	3. I've been saying to myself "this isn't real.".
		8	8. I've been refusing to believe that it has happened.
		Substance 4	4. I've been using alcohol or other drugs to make myself feel better.
		11	11. I've been using alcohol or other drugs to help me get through it.
		Beh disen 6	6. I've been giving up trying to deal with it.
		16	16. I've been giving up the attempt to cope.
		Venting 9	9. I've been saying things to let my unpleasant feelings escape.
		21	21. I've been expressing my negative feelings.
		Self-blame 13	13. I've been criticizing myself.
		26	26. I've been blaming myself for things that happened.
Emotion-focused	10	emotional 5	5. I've been getting emotional support from others.
		15	15. I've been getting comfort and understanding from someone.
		Positive ref 12	12. I've been trying to see it in a different light, to make it seem more positive.
		17	17. I've been looking for something good in what is happening.
		Humour 18	18. I've been making jokes about it.
		28	28. I've been making fun of the situation.
		Acceptance 20	20. I've been accepting the reality of the fact that it has happened.
		24	24. I've been learning to live with it.
		Religion 22	22. I've been trying to find comfort in my religion or spiritual beliefs.
		27	27. I've been praying or meditating.
GFD Knowledge (0-11; NO REVERSAL)			
Food Quiz	11	1	Modified starch
		2	Potato starch
		3	Monosodium glutamate
		4	Xanthum gum
		5	Modified wheat starch
		6	Colouring
		7	Hydrolysed vegetable protein (HVP)
		8	Textured Vegetable protein (TVP)
		9	Yeast extract
		10	Vanilla essence
		11	Rusk
Gluten Free Dietary Self-Care (1-4 self-care, 5 & 6 concern; NO REVERSAL)			
GDF scale	6	1	How often have you knowingly eaten foods containing gluten while at home?
		2	How often have you knowingly eaten foods containing gluten when away from home?
		3	How well do you stick to your gluten-free diet when you are at home?
		4	How well do you stick to your gluten-free diet when you are away from home?
		5	How concerned are you about accidental gluten-ingestion?
		6	How harmful do you feel accidental gluten-exposure is to your health?

Appendix F. Independent t-test output of analyses of gender effects across demographic and outcome variables.

Group Statistics

	Gender	N	Mean	Std. Deviation	Std. Error Mean
Age	female	64	52.92	14.321	1.790
	male	32	55.72	13.248	2.342
Clinician Rated GFD Dietary Self-care	female	44	4.705	.6035	.0910
	male	18	4.694	.5461	.1287
CD Antibodies level	female	43	6.5372	12.57804	1.91813
	male	17	5.0118	8.35949	2.02747
Self-efficacy	female	62	280.8841	48.31780	6.13637
	male	31	290.3059	36.01548	6.46857
General Wellbeing	female	64	21.1406	4.88882	.61110
	male	32	22.2500	4.38472	.77512
Coping (problem-focussed)	female	63	9.8626	4.29996	.54174
	male	31	10.7283	4.28673	.76992
Coping (dysfunctional)	female	63	14.8271	4.50434	.56749
	male	31	14.9135	4.56590	.82006
Coping (emotion-focussed)	female	63	16.4582	5.29050	.66654
	male	29	18.2414	4.39688	.81648
HRQoLTotal	female	59	107.1862	17.75633	2.31168
	male	28	109.2491	16.71101	3.15808
Psychological Distress	female	64	12.1145	11.94262	1.49283
	male	32	13.0668	12.34150	2.18169
Self Reported GFD Dietary Self-care	female	64	18.2359	2.96675	.37084
	male	32	18.4063	2.21227	.39108

Independent Samples t-tests for Gender Differences

		Levene's Test for Equality of Variances		t-test for Equality of Means						
									95% Confidence Interval of the Difference	
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper
Age	Equal variances assumed	.184	.669	-.924	94	.358	-2.797	3.026	-8.805	3.211
	Equal variances not assumed			-.949	66.619	.346	-2.797	2.948	-8.681	3.087
Clinician Rated GFD Dietary Self-care	Equal variances assumed	.001	.970	.061	60	.951	.0101	.1645	-.3189	.3391
	Equal variances not assumed			.064	34.795	.949	.0101	.1576	-.3099	.3301
CD Antibodies level	Equal variances assumed	.508	.479	.460	58	.647	1.52544	3.31445	-5.10916	8.16005
	Equal variances not assumed			.547	44.024	.587	1.52544	2.79104	-4.09944	7.15032
Self-efficacy	Equal variances assumed	1.950	.166	-.960	91	.340	-9.42176	9.81912	-28.92623	10.08271
	Equal variances not assumed			-1.057	77.445	.294	-9.42176	8.91613	-27.17442	8.33090
General Wellbeing	Equal variances assumed	.186	.668	-1.084	94	.281	-1.10938	1.02375	-3.14206	.92331
	Equal variances not assumed			-1.124	68.493	.265	-1.10938	.98704	-3.07873	.85998
Coping (problem-focussed)	Equal variances assumed	.018	.895	-.919	92	.361	-.86569	.94241	-2.73741	1.00603
	Equal variances not assumed			-.920	59.950	.361	-.86569	.94142	-2.74883	1.01746

Independent Samples t-tests for Gender Differences

		Levene's Test for Equality of Variances		t-test for Equality of Means						
									95% Confidence Interval of the Difference	
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper
Coping (dysfunctional)	Equal variances assumed	.293	.589	-.087	92	.931	-.08644	.99262	-2.05787	1.88500
	Equal variances not assumed			-.087	59.059	.931	-.08644	.99727	-2.08193	1.90906
Coping (emotion-focussed)	Equal variances assumed	3.776	.055	-1.580	90	.118	-1.78319	1.12863	-4.02541	.45903
	Equal variances not assumed			-1.692	64.766	.095	-1.78319	1.05400	-3.88832	.32194
HRQoLTotal	Equal variances assumed	.445	.506	-.516	85	.607	-2.06290	4.00018	-10.01632	5.89052
	Equal variances not assumed			-.527	56.177	.600	-2.06290	3.91374	-9.90251	5.77671
Psychological Distress	Equal variances assumed	.001	.972	-.364	94	.716	-.95230	2.61445	-6.14335	4.23875
	Equal variances not assumed			-.360	60.318	.720	-.95230	2.64354	-6.23960	4.33499
Self Reported GFD Dietary Self-care	Equal variances assumed	.526	.470	-.287	94	.775	-.17039	.59344	-1.34868	1.00789
	Equal variances not assumed			-.316	79.990	.753	-.17039	.53895	-1.24294	.90215

Appendix G. Sample Demographic Information.

Table showing demographic data for the sample (Where n=<96 this is due to missing data)

Diagnosis	N	%
By intestinal biopsy and blood test	76	79.2
By intestinal biopsy or blood test alone	19	19.8
Age at diagnosis		
16 years and under	5	5.2
17-45 years	45	46.9
45 -65 years	37	38.5
65 years and older	8	8.3
Co-morbidity		
No of comorbid physical conditions		
No other conditions	57	59.4
1 other condition	27	28.1
2 other conditions	14	12.6
No of comorbid mental health conditions		
No mental health conditions	92	95.8
1 or more mental health conditions	4	4.2
Highest educational attainment		
University Qualifications	21	21.8
Vocational training/qualifications	27	28.1
School education with qualifications	35	36.5
School education, no qualifications	13	13.5
Highest level of Occupation		
Professional/ Managerial or technical	60	62.5
Non manual skilled/ Manual skilled	21	21.9
Partly skilled/unskilled	9	9.4
Home-maker	4	4.2
Relationship status		
Single	9	9.4
Cohabiting or married	74	77.1
Divorced or separated	7	7.3
Widowed	6	6.3
Membership of Coeliac UK		
Yes	70	72.9
No	26	27.1
Frequency of dietician appointments		
Every 6 months	13	13.5
Every year	47	49
Every 2 years	27	28.1

3 years or more	8	8.3
Ethnicity		
White British	92	95.8
White other	1	1
Asian	2	2.1

Appendix H. Internal Consistency Achieved by Each Scale.

Measure and Sub-scale	N	Number of items	Cronbach's Alpha
IPQ-R			
Identity	91	20	0.80**
Timeline (acute/chronic)	92	6	0.68**
Consequences	95	6	0.76**
Personal control	92	6	0.85
Treatment control	96	5	0.51*
Illness coherence	95	5	0.18**
Timeline (cyclical)	96	4	0.89
Emotional representations	96	6	0.87**
GWBI			
Total	96	6	0.86
CDQ			
Gastrointestinal symptoms	96	7	0.68**
Emotional wellbeing	93	7	0.69**
Social restrictions	72	7	0.54**
Disease related worries	85	7	0.83**
Total score	62	28	0.89**
DASS			
Depression	96	7	0.91**
Anxiety	95	7	0.81
Stress	96	7	0.87**
Total	93	21	0.95
CD-SES	74	34	0.97*
Brief COPE			
Emotional-focused	90	10	0.75*
Problem-focused	91	6	0.81**
Dysfunctional	90	12	0.83**
Total	87	28	0.89**
Gluten Free Diet			
Dietary Self-care	96	4	0.91**
Concerns about Gluten Ingestion	96	2	0.78
Total score	96	6	0.81**
GFD Knowledge	96	11	0.59**

Appendix I. Pearson's Correlation Table showing the relationships between Illness Representations and all outcomes.

Correlations between Illness Representations and all outcome measures

		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. Identity	Pearson Correlation	1	.031	.162	.151	.025	.257**	-.048	.207*	-.029	-.275**	-.317**	.308**	-.061	-.013	.027
	Sig. (1-tailed)		.383	.058	.072	.405	.006	.322	.022	.391	.003	.001	.001	.323	.461	.399
	N	96	92	96	95	96	95	96	96	93	96	87	96	60	62	96
2. Time Chronicity	Pearson Correlation	.031	1	-.045	.209*	.217*	.195*	.212*	-.082	-.012	-.168	-.121	.164	.100	.062	.037
	Sig. (1-tailed)	.383		.335	.023	.019	.031	.021	.218	.454	.055	.136	.059	.228	.320	.362
	N	92	92	92	92	92	92	92	92	90	92	84	92	58	60	92
3.Time Cyclical	Pearson Correlation	.162	-.045	1	-.221*	-.124	.218*	-.404**	.426**	-.388**	-.367**	-.446**	.341**	.254*	-.246*	-.220*
	Sig. (1-tailed)	.058	.335		.016	.115	.017	.000	.000	.000	.000	.000	.000	.025	.027	.015
	N	96	92	96	95	96	95	96	96	93	96	87	96	60	62	96
4. Control Personal	Pearson Correlation	.151	.209*	-.221*	1	.634**	.152	.302**	-.198*	.054	.027	.067	-.038	-.034	.305**	.105
	Sig. (1-tailed)	.072	.023	.016		.000	.071	.001	.027	.306	.397	.268	.356	.399	.008	.156

Correlations between Illness Representations and all outcome measures

		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
	N	95	92	95	95	95	95	95	95	92	95	87	95	60	62	95
5. Control Treatment	Pearson Correlation	.025	.217*	-.124	.634**	1	-.073	.230*	-.223*	-.044	-.020	.145	-.010	.118	.155	.004
	Sig. (1-tailed)	.405	.019	.115	.000		.242	.012	.014	.337	.424	.091	.461	.184	.115	.483
	N	96	92	96	95	96	95	96	96	93	96	87	96	60	62	96
6. Consequence	Pearson Correlation	.257**	.195*	.218*	.152	-.073	1	-.142	.434**	.073	-.386**	-.529**	.428**	-.085	.176	.198*
	Sig. (1-tailed)	.006	.031	.017	.071	.242		.085	.000	.246	.000	.000	.000	.260	.085	.027
	N	95	92	95	95	95	95	95	95	92	95	87	95	60	62	95
7. Coherence	Pearson Correlation	-.048	.212*	-.404**	.302**	.230*	-.142	1	-.451**	.132	.208*	.278**	-.161	-.086	.181	.070
	Sig. (1-tailed)	.322	.021	.000	.001	.012	.085		.000	.104	.021	.005	.059	.257	.080	.247
	N	96	92	96	95	96	95	96	96	93	96	87	96	60	62	96
8. Emotional Representations	Pearson Correlation	.207*	-.082	.426**	-.198*	-.223*	.434**	-.451**	1	-.116	-.376**	-.539**	.458**	.123	-.017	.018
	Sig. (1-tailed)	.022	.218	.000	.027	.014	.000	.000		.135	.000	.000	.000	.175	.448	.431
	N	96	92	96	95	96	95	96	96	93	96	87	96	60	62	96

Correlations between Illness Representations and all outcome measures

		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
9. Self-efficacy	Pearson Correlation	-.029	-.012	-.388**	.054	-.044	.073	.132	-.116	1	.239*	.251*	-.188*	-.397**	.747**	.805**
	Sig. (1-tailed)	.391	.454	.000	.306	.337	.246	.104	.135		.011	.010	.036	.001	.000	.000
	N	93	90	93	92	93	92	93	93	93	93	85	93	59	61	93
10. General Wellbeing	Pearson Correlation	-.275**	-.168	-.367**	.027	-.020	-.386**	.208*	-.376**	.239*	1	.719**	-.795**	-.106	.150	.127
	Sig. (1-tailed)	.003	.055	.000	.397	.424	.000	.021	.000	.011		.000	.000	.210	.122	.110
	N	96	92	96	95	96	95	96	96	93	96	87	96	60	62	96
11. Health- Related QoL	Pearson Correlation	-.317**	-.121	-.446**	.067	.145	-.529**	.278**	-.539**	.251*	.719**	1	-.711**	.021	.164	.145
	Sig. (1-tailed)	.001	.136	.000	.268	.091	.000	.005	.000	.010	.000		.000	.439	.111	.090
	N	87	84	87	87	87	87	87	87	85	87	87	87	55	57	87
12. Psychological Distress	Pearson Correlation	.308**	.164	.341**	-.038	-.010	.428**	-.161	.458**	-.188*	-.795**	-.711**	1	.101	-.076	-.062
	Sig. (1-tailed)	.001	.059	.000	.356	.461	.000	.059	.000	.036	.000	.000		.220	.279	.276
	N	96	92	96	95	96	95	96	96	93	96	87	96	60	62	96
13. CD Antibody levels	Pearson Correlation	-.061	.100	.254*	-.034	.118	-.085	-.086	.123	-.397**	-.106	.021	.101	1	-.444**	-.376**

Correlations between Illness Representations and all outcome measures

		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
	Sig. (1-tailed)	.323	.228	.025	.399	.184	.260	.257	.175	.001	.210	.439	.220		.000	.002
	N	60	58	60	60	60	60	60	60	59	60	55	60	60	60	60
14. Clinician Rated Dietary Self-care	Pearson Correlation	-.013	.062	-.246*	.305**	.155	.176	.181	-.017	.747**	.150	.164	-.076	-.444**	1	.809**
	Sig. (1-tailed)	.461	.320	.027	.008	.115	.085	.080	.448	.000	.122	.111	.279	.000		.000
	N	62	60	62	62	62	62	62	62	61	62	57	62	60	62	62
15. Self Reported GFD	Pearson Correlation	.027	.037	-.220*	.105	.004	.198*	.070	.018	.805**	.127	.145	-.062	-.376**	.809**	1
	Sig. (1-tailed)	.399	.362	.015	.156	.483	.027	.247	.431	.000	.110	.090	.276	.002	.000	
	N	96	92	96	95	96	95	96	96	93	96	87	96	60	62	96

**. Correlation is significant at the 0.01 level (1-tailed).

*. Correlation is significant at the 0.05 level (1-tailed).

Appendix J. Table Showing Regression Analyses Investigating Hypothesised Relationships Between Illness Representations and All Outcomes.

Dependent Variable		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	95.0% Confidence Interval for B		Collinearity Statistics	
		B	Std. Error	Beta			Lower Bound	Upper Bound	Tolerance	VIF
Quality of life	(Constant)	155.867	15.789		9.872	.000	124.420	187.314		
	Identity	-.953	.489	-.167	-1.950	.055	-1.927	.020	.907	1.103
R^2= 0.493; F = 10.566; p <0.01	Timeline Chronic	-.428	.544	-.068	-.787	.434	-1.513	.656	.895	1.117
	Consequence	-1.096	.367	-.295	-2.985	.004	-1.828	-.365	.682	1.466
	Personal Control	.121	.505	.028	.240	.811	-.885	1.128	.502	1.992
	Treatment Control	.269	.602	.049	.446	.657	-.931	1.468	.554	1.805
	Timeline Cyclical	-1.202	.444	-.250	-2.707	.008	-2.087	-.318	.782	1.278
	Emotional Representation	-.884	.331	-.270	-2.668	.009	-1.543	-.224	.650	1.538
Psychological distress	(Constant)	-27.253	11.822		-2.305	.024	-50.761	-3.745		
	Identity	.823	.368	.206	2.236	.028	.091	1.554	.884	1.131
	Timeline Chronic	.605	.390	.143	1.553	.124	-.170	1.381	.888	1.126
R^2= 0.606; F = 6.976; p < 0.01	Consequence	.592	.282	.224	2.103	.038	.032	1.152	.666	1.502
	Personal Control	-.485	.383	-.155	-1.264	.210	-1.247	.278	.500	1.998
	Treatment Control	.585	.458	.150	1.278	.205	-.325	1.495	.548	1.824
	Timeline Cyclical	.457	.333	.136	1.374	.173	-.204	1.118	.772	1.295
	Emotional	.646	.255	.274	2.534	.013	.139	1.153	.642	1.557

Dependent Variable		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	95.0% Confidence Interval for B		Collinearity Statistics	
	Representation	B	Std. Error	Beta			Lower Bound	Upper Bound	Tolerance	VIF
General Wellbeing	(Constant)	36.935	4.889		7.554	.000	27.212	46.658		
	Identity	-.266	.152	-.169	-1.750	.084	-.569	.036	.884	1.131
R^2= 0.308; F = 5.336; p < 0.01	Timeline Chronic	-.231	.161	-.138	-1.433	.156	-.552	.090	.888	1.126
	Consequence	-.239	.116	-.228	-2.052	.043	-.471	-.007	.666	1.502
	Personal Control	.179	.159	.145	1.126	.263	-.137	.494	.500	1.998
	Treatment Control	-.239	.189	-.155	-1.261	.211	-.615	.138	.548	1.824
	Timeline Cyclical	-.275	.138	-.206	-1.998	.049	-.548	-.001	.772	1.295
	Emotional Representation	-.157	.105	-.168	-1.485	.141	-.366	.053	.642	1.557
Clinician rated dietary adherence	(Constant)	3.284	.887		3.703	.001	1.504	5.064		
	Identity	-.023	.026	-.130	-.889	.378	-.075	.029	.763	1.310
	Timeline Chronic	-.017	.027	-.092	-.633	.530	-.072	.038	.779	1.284
R^2= 0.15; F = 1.313; p = 0.263	Consequence	.028	.023	.204	1.232	.223	-.018	.074	.594	1.684
	Personal Control	.043	.033	.259	1.297	.200	-.023	.109	.411	2.434
	Treatment Control	.013	.031	.073	.417	.678	-.049	.074	.530	1.887
	Timeline Cyclical	-.026	.025	-.167	-1.023	.311	-.077	.025	.617	1.620
	Emotional Representation	.019	.020	.159	.942	.351	-.021	.059	.575	1.739
Self reported dietary	(Constant)	17.114	3.120		5.486	.000	10.911	23.318		

Dependent Variable		Unstandardized Coefficients		Standardized Coefficients			95.0% Confidence Interval for B		Collinearity Statistics	
		B	Std. Error	Beta	t	Sig.	Lower Bound	Upper Bound	Tolerance	VIF
self-care	Identity	-.022	.097	-.025	-.226	.822	-.215	.171	.884	1.131
	Timeline Chronic	-.016	.103	-.018	-.160	.873	-.221	.188	.888	1.126
R^2 = 0.090; F = 1.187; p = 0.319	Consequence	.130	.074	.223	1.748	.084	-.018	.278	.666	1.502
	Personal Control	.026	.101	.037	.254	.800	-.175	.227	.500	1.998
	Treatment Control	-.011	.121	-.013	-.091	.928	-.251	.229	.548	1.824
	Timeline Cyclical	-.184	.088	-.248	-2.092	.040	-.358	-.009	.772	1.295
	Emotional Representation	.024	.067	.046	.351	.726	-.110	.157	.642	1.557
Self-efficacy	(Constant)	340.296	50.740		6.707	.000	239.358	441.234		
	Identity	.187	1.566	.013	.119	.905	-2.929	3.303	.889	1.125
R^2= 0.173; F = 2.450; p = 0.02	Timeline Chronic	-.649	1.680	-.041	-.386	.700	-3.992	2.694	.902	1.109
	Consequence	1.834	1.203	.186	1.525	.131	-.559	4.228	.677	1.477
	Personal Control	-.435	1.623	-.038	-.268	.789	-3.665	2.794	.502	1.991
	Treatment Control	-.810	1.939	-.057	-.418	.677	-4.667	3.047	.549	1.822
	Timeline Cyclical	-5.207	1.415	-.422	-3.680	.000	-8.022	-2.392	.766	1.305
	Emotional Representation	-.343	1.089	-.040	-.315	.753	-2.509	1.822	.642	1.559
CD Antibodies	(Constant)	-17.500	13.300		-1.316	.194	-44.215	9.215		
	Identity	-.285	.386	-.115	-.738	.464	-1.059	.490	.756	1.323
R^2= 0.88; F = 0.690;	Timeline Chronic	.144	.410	.054	.350	.728	-.681	.968	.760	1.315

Dependent Variable p = 0.680		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	95.0% Confidence Interval for B		Collinearity Statistics	
		B	Std. Error	Beta			Lower Bound	Upper Bound	Tolerance	VIF
	Consequence	.030	.351	.015	.085	.932	-.676	.736	.598	1.672
	Personal Control	.242	.501	.102	.483	.631	-.764	1.248	.407	2.460
	Treatment Control	.320	.456	.130	.702	.486	-.595	1.235	.534	1.872
	Timeline Cyclical	.421	.378	.193	1.114	.271	-.339	1.181	.608	1.645
	Emotional Representation	.279	.302	.165	.923	.360	-.328	.887	.573	1.744

Appendix K. Correlation Tables Investigating Coping.

All Analyses Related to the Relationships Between Illness Representations, Coping, and Outcomes.

Correlations between illness representations and coping

		1	2	3	4	5	6	7	8	9	10	11	12
1. Identity	Pearson Correlation	1	.031	.257*	.151	.025	-.048	.162	.207*	-.029	.163	.209*	.118
	Sig. (2-tailed)		.767	.012	.145	.810	.645	.116	.043	.782	.118	.043	.263
	N	96	92	95	95	96	96	96	96	93	94	94	92
2. Timechronicity	Pearson Correlation	.031	1	.195	.209*	.217*	.212*	-.045	-.082	-.012	.111	.060	-.062
	Sig. (2-tailed)	.767		.063	.045	.037	.042	.670	.436	.909	.297	.575	.564
	N	92	92	92	92	92	92	92	92	90	90	90	88
3. Consequence	Pearson Correlation	.257*	.195	1	.152	-.073	-.142	.218*	.434**	.073	.302**	.370**	.242*
	Sig. (2-tailed)	.012	.063		.142	.484	.169	.034	.000	.492	.003	.000	.021
	N	95	92	95	95	95	95	95	95	92	93	93	91
4. Controlpersonal	Pearson Correlation	.151	.209*	.152	1	.634**	.302**	-.221*	-.198	.054	.009	.052	.058
	Sig. (2-tailed)	.145	.045	.142		.000	.003	.032	.055	.612	.934	.623	.583
	N	95	92	95	95	95	95	95	95	92	93	93	91
5. Control treatment	Pearson Correlation	.025	.217*	-.073	.634**	1	.230*	-.124	-.223*	-.044	-.089	-.090	-.059
	Sig. (2-tailed)	.810	.037	.484	.000		.024	.230	.029	.674	.392	.387	.576
	N	96	92	95	95	96	96	96	96	93	94	94	92

Correlations between illness representations and coping

		1	2	3	4	5	6	7	8	9	10	11	12
6. Coherence	Pearson Correlation	-.048	.212*	-.142	.302**	.230*	1	-.404**	-.451**	.132	-.101	-.214*	-.126
	Sig. (2-tailed)	.645	.042	.169	.003	.024		.000	.000	.208	.335	.039	.233
	N	96	92	95	95	96	96	96	96	93	94	94	92
7. Timecyclical	Pearson Correlation	.162	-.045	.218*	-.221*	-.124	-.404**	1	.426**	-.388**	.081	.217*	-.002
	Sig. (2-tailed)	.116	.670	.034	.032	.230	.000		.000	.000	.439	.036	.982
	N	96	92	95	95	96	96	96	96	93	94	94	92
8. Emotional Representations	Pearson Correlation	.207*	-.082	.434**	-.198	-.223*	-.451**	.426**	1	-.116	.240*	.358**	.236*
	Sig. (2-tailed)	.043	.436	.000	.055	.029	.000	.000		.269	.020	.000	.023
	N	96	92	95	95	96	96	96	96	93	94	94	92
9. Self-efficacy	Pearson Correlation	-.029	-.012	.073	.054	-.044	.132	-.388**	-.116	1	-.065	-.086	-.051
	Sig. (2-tailed)	.782	.909	.492	.612	.674	.208	.000	.269		.542	.416	.632
	N	93	90	92	92	93	93	93	93	93	91	91	89
10. Problem-focused coping	Pearson Correlation	.163	.111	.302**	.009	-.089	-.101	.081	.240*	-.065	1	.510**	.596**
	Sig. (2-tailed)	.118	.297	.003	.934	.392	.335	.439	.020	.542		.000	.000
	N	94	90	93	93	94	94	94	94	91	94	94	92
11. Dysfunctional coping	Pearson Correlation	.209*	.060	.370**	.052	-.090	-.214*	.217*	.358**	-.086	.510**	1	.430**
	Sig. (2-tailed)	.043	.575	.000	.623	.387	.039	.036	.000	.416	.000		.000
	N	94	90	93	93	94	94	94	94	91	94	94	92

Correlations between illness representations and coping

		1	2	3	4	5	6	7	8	9	10	11	12
12. Emotional-focused Coping	Pearson Correlation	.118	-.062	.242*	.058	-.059	-.126	-.002	.236*	-.051	.596**	.430**	1
	Sig. (2-tailed)	.263	.564	.021	.583	.576	.233	.982	.023	.632	.000	.000	
	N	92	88	91	91	92	92	92	92	89	92	92	92

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

		1	2	3	4	5	6	7	8
1 Emotional Representations	Pearson Correlation	1	.434**	.240**	.358**	.236*	-.539**	.458**	-.376**
	Sig. (1-tailed)		.000	.010	.000	.012	.000	.000	.000
	N	96	95	94	94	92	87	96	96
2. Consequence Beliefs	Pearson Correlation	.434**	1	.302**	.370**	.242*	-.529**	.428**	-.386**
	Sig. (1-tailed)	.000		.002	.000	.011	.000	.000	.000
	N	95	95	93	93	91	87	95	95
3. Problem-focused Coping	Pearson Correlation	.240**	.302**	1	.510**	.596**	-.476**	.455**	-.408**
	Sig. (1-tailed)	.010	.002		.000	.000	.000	.000	.000
	N	94	93	94	94	92	85	94	94
4. Dysfunctional Coping	Pearson Correlation	.358**	.370**	.510**	1	.430**	-.617**	.673**	-.533**
	Sig. (1-tailed)	.000	.000	.000		.000	.000	.000	.000
	N	94	93	94	94	92	85	94	94
5. Emotion-Focussed	Pearson Correlation	.236*	.242*	.596**	.430**	1	-.250*	.269**	-.216*

		1	2	3	4	5	6	7	8
Coping	Sig. (1-tailed)	.012	.011	.000	.000		.011	.005	.019
	N	92	91	92	92	92	84	92	92
6. Health-Related QoL	Pearson Correlation	-.539**	-.529**	-.476**	-.617**	-.250*	1	-.711**	.719**
	Sig. (1-tailed)	.000	.000	.000	.000	.011		.000	.000
	N	87	87	85	85	84	87	87	87
7. Psychological Distress	Pearson Correlation	.458**	.428**	.455**	.673**	.269**	-.711**	1	-.795**
	Sig. (1-tailed)	.000	.000	.000	.000	.005	.000		.000
	N	96	95	94	94	92	87	96	96
8. General Wellbeing	Pearson Correlation	-.376**	-.386**	-.408**	-.533**	-.216*	.719**	-.795**	1
	Sig. (1-tailed)	.000	.000	.000	.000	.019	.000	.000	
	N	96	95	94	94	92	87	96	96

**. Correlation is significant at the 0.01 level (1-tailed).

*. Correlation is significant at the 0.05 level (1-tailed).